



ARC (ARACHNOIDITIS) NEWSLETTER

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A Non-Profit Organization created for the Study of the Causes, the Diagnosis and the Treatment of ARACHNOIDITIS.

EDITOR'S PAGE

This latest quarter has been characterized by confirmation of what has been suspected from years that manipulations and invasions of the vertebral canal (that is the conduit within the spine that contains the dural sac, and its elements (spinal cord, nerve roots and cerebrospinal fluid) are beginning to be proven harmful. By this I mean that a number of articles have began to appear warning that all manipulations, injections, implantation, radio-stimulation of the spine or its elements are not only not helpful, but in many instances can be right out harmful.

In reality, allow me to recognize that the spine is a wonderfully made organ; it is astonishing how it supports us for over 80 years. But if we stop to think for a moment how delicately are each vertebra placed on top of each other and the different forms, shapes and sizes of the vertebrae of the cervical, thoracic, lumbar and sacral areas are made specifically designed for the function of the neck, thorax, lower back and "tail bone". How the external bony structures protect the very delicate nerve roots, the rootlets and specially the spinal cord, it is incredible. This latest organ is the most sophisticated set of computers composed of multiple microscopic receptors, and transmitters that carry electrical micro-signals from the peripheral nerves to the nerve roots spinal cord and into the brain. There again by an even more complex set of software the signals are identified, classified and an immediate response initiated following the same path, but in reverse order that would make our leg pull away from a painful stimuli.

The shape, thickness, elasticity and contour of each disc placed in between the vertebrae seems to be tailored one at a time to fit the bone above and the one below. How the ligaments keep each vertebra next to the one above and below is unique, as they allow us enough movement, bend over, rotate enough but not exceedingly so. The small orifices through which the nerve roots leave the spine are only millimeters wide. In spite the technological advancements and attempts to replace it they are never the same and although a few cases have had success in severe trauma, the elective fusions and vertebral replacements are far from being successful in series.

This is just a simple explanation of the thousands of transmission-reception-transmission sequences that go on every day of our lives. Within these tissues there are also chemical substances released that initiate complex cycles of perception of various sensations, heat, touch, pain, etc. which in turn precipitate release of other substances that would either, reduce them or enlarge them, block them or transmit them, just to mention some of their functions. One cannot help to think that this marvelous organ of which I just have mentioned only few of its wonderfully built anatomy and even more amassing functions has to have been set up, planned and placed in us so we can function by a Mighty Intelligent and Superior Being.

In watching my grandchildren do gymnastics, play and do all what children do. It is incredible how they flip, turn and bump their bodies with the corresponding spinal trauma. More admirable is how their spines tolerate these frequent injuries without permanent harm. Then we go through adolescence and early adulthood with sport participation, again injuring and re-injuring our spines. The delicate systems that I mentioned keep on functioning in spite everything we do to harm it.

In middle age all these micro or macro traumas begin to have an impact on our spine, early degeneration of discs and joints are more evident in those extremely active and especially in those that engaged in “contact sports”. Injuries in this stage are not as well tolerated and we begin to have stiff necks, sore backs and those discs that have tolerated twisting, bending, jumping suddenly loose some water, become less flexible, begin to crack, bulge, sag and rupture if another trauma occurs.

We only have one spine, there is no replacement, transplant or temporary substitute (like kidney dialysis or heart-lung machine); this is it what you have, what you were given, and how you treated it. The benefits of exercise fitness have to be weighted against the effects of repeated trauma to back, nerves, joints, muscles, ligaments, etc. In other words the old adage “there is no free lunch” applies here, too. We have been led to believe that we can exercise forever and we can, but moderately. Although joints can be replaced, the new metal joints are never the same as those given to us by the Great Creator, No Sir.

We only have one spine how we treated in our earlier years, how it sustained the trauma from accidents, falls and other events in our daily life (jobs, sports, etc) has a definite impact in how easy or miserable we are going to spend our later years. So please take care of your back, support it as much as you can and do not unnecessarily injure it.

PUBLICATIONS THAT MAY BE OF INTEREST TO THE ARACHNOIDITIS READERSHIP

On this vein I would like to point out to the readership some articles that have appeared in the medical literature, lately.

Deyo RA, et al: Spinal-Fusion surgery- A case for restraint. New England Journal of Medicine 2004:350:722-726.

R.A. Deyo and his collaborators from the University of Washington in Seattle for years have analyzed the effect of work related spinal injuries and specially the effectiveness of all treatments that have been proposed for them. His latest report entitled "Spinal-Fusion surgery- A case for restraint" published in the prestigious *New England Journal of Medicine* 2004;350:722-726. This group points out that Americans are "being fused 7 times more often than equal population groups in other industrialized patients; and believe me is not because we have a better health care system because many of you might have experience the shortcomings of it. The number of spinal fusions in the US has risen by 77% in the period between 1996-2001; while knee and hip replacements have increased by 13 and 14% respectively. The average hospital bill exceeds 34 000 dollars, without the professional fee. The indications are various but not consistent, many are planned after repeated failed laminectomies. Among them is the procedure called discogram in which dye is injected inside of discs, if enough dye is injected it produces pain as the amount of any fluid that discs can have is very small (1 to 2 ml). If the patient has pain it is interpreted as a "pain generator" and so an indication for removal of the disc and fusion of the two adjacent vertebrae into one. The fact is that this is a provocative, very debatable test usually done by the same surgeon or team who will be doing the fusion so it has questionable motives. In fact any disc damage can be identified in a well taken and properly read MRI of the lumbar spine. These testing procedures are very much in doubt as their justification and the motivation for fusions or discectomy. In properly selected patient's laminectomy are proven as effective as laminectomy and fusion. Most of the series published have fundamental problems with great number of "desertions", in other words in other words losing many patients at follow up by the same surgical team. The absent patients have been considered as successes where as in fact they are either in the waiting rooms of other physicians or in pain clinics where they frequently end up with the diagnosis of "failed back syndrome". More serious is the weak association between solid fusions and pain relief. Even when the fusion succeeds in making one vertebra out of two but the patient's pain is not relieved; for all practical purposes the fusion failed to relief the patient's primordial symptom. The authors concluded that this type of surgery remains controversial, the primary clinical outcomes that have been used are subjective and the incidence of complications such as failure to fuse, arachnoiditis, damage to adjacent muscle, hardware (screws) misplacement and breakage are too numerous to accept this form of treatment based on the poorly executed clinical trials. Besides the cost is excessive for the benefits obtain.

THIS ARTICLE IS A MUST FOR ANYONE CONTEMPLATING A SPINE FUSION.

Merrill DG: Hoffman's glasses: Evidence-Based medicine and the search for Quality in the literature of Interventional Pain medicine. *Regional Anesthesia and Pain Medicine*, 2003;28:547-560.

Following the line of misleading therapies I now will like for the readership to direct their attention to an article that appeared in the *Regional Anesthesia and Pain Medicine*, 2003;28:547-560, entitled "Hoffman's glasses: Evidence-Based medicine and the search for Quality in the literature of Interventional Pain medicine" authored

by D. G. Merrill. Cleverly, the author relate the “state of the Art of Interventions of the spine for the treatment of pain” to the opera “The tales of Hoffman” personified by a character that with a special set of magic glasses the wearer can see anything he wants to see. In Essence Dr. Merrill conducted an extensive review of the medical literature concerned interventional therapy procedures proposed for the treatment of chronic non-cancer pain using a rigorous criteria that included anti-bias controls, controlled comparisons and outcome measurements among other parameters. Procedures evaluated included among others, less frequently performed:

Epidural neurolysis

Radiofrequency block of facet

Intralaminar epidural steroid

Discography

Sympathetic block

Diagnostic Nerve blocks

Spinal cord stimulators

The procedures including names as “perineural”, “selective, transforaminal and periradicular “were all grouped into one category

Citing the onset of Modern Medicine as “the era when diagnosis and treatment sank their roots into facts” (Berwick DM. *Qual Man Health Care* 1992-1:1-8), the author concluded that “the practice of invasive pain medicine teeters at a particular critical juncture in its nascent development, crippled by a lack of vigorous self-evaluation of its role in the treatment of chronic pain”. Eloquently Dr. Merrill insisted that the literature provides scant proof of long-term benefit for those patients treated with these procedures. He warned that many interventional pain therapies will not appear as clinical guidelines. However no body seems to listen as the third party payees are reimbursing for it. But he cautions that “in the increasingly frantic scramble for the health dollar, interventional therapies for chronic pain and their advocates may be marginalized.” He also advised “investigators need to produce difficult, expensive, controlled and long term studies of each of these procedures”.

COMMENTARY: Frequently in our Web site I am asked to advice patients whether to have or not such and such procedure. By regulations I am prevented to give advice to patients that I have not examined. But I can certainly refer patients to these objective analytic studies; from the authors commentaries anyone should be able to make a more and better informed decision. Remember not only the cost/benefit ratio has to be considered but also you must consider that “even if it does not help, it definitely should not harm”, that is as important as would it cure my pain?

Carter ML: Spinal Cord Stimulation in chronic pain: a review of the evidence. *Anaesthesia and Intensive Care* 2004;32:11-21.

Last but by no means least I also like the readership to consult an excellently executed analysis of

SPINAL CORD STIMULATION IN CHRONIC PAIN; A REVIEW OF THE EVIDENCE. Authored by M.L. Carter FRCA, FANZCA, FFPMANZCA that

appeared in the February issue of *Anaesthesia and Intensive Care* 2004;32:11-21.

Because he was unable to find one single report that would satisfy the stringent methodology for the most analytic criteria, that is meta-analysis, among the publications describing experiences with Spinal Cord Stimulation (SCS), a special criteria score for analysis was created. Moreover, it was found that most of the studies did not comply fully with the principles set up for “high quality randomized controlled trials”. All articles published in over 7 different languages, related to SCS, were reviewed. He analyzed the published articles by indications. As far as the articles referring to “neuropathic pain” which is the type of pain experienced by patients with Arachnoiditis, he concluded “Spinal cord lesions have not responded well to SCS. This is possibly due to the absence of fibers to be stimulated. The technique has also proved disappointing in post-herpetic neuralgia” and in post-amputation states, “SCS does not compare favorably with other methods of pain relief”. The author concluded that the assessment of the place of SCS is greatly limited by the quality of clinical research that has been performed. Although there seems to show promise in patients with critical limb ischemia and in chronic intractable angina, its application in chronic back pain, complex regional pain syndrome and neuropathic pain, remains to be proven. He recommended that since “double blind studies are not possible, the clinical studies should be randomized, controlled and comparison trials” then, the true impact of SCS on functional, psychological and pharmacological outcomes may be identified and quantified”. Maybe, that is why neurosurgeon Norman Shealy, the first proponent of SCS (Anesth Analg 1967:46:489-491), after extensive experience, in 1992 expressed skepticism on its effectiveness and because an unfavorable cost/benefit ratio he stated that it had little application in pain control (Shealy CN: Spinal Cord Stimulation: 1973 to present (comment). Am J Pain Managem 1992:2:43.

Domino KB, Fitzgibbon DR: Clinical Lessons in Chronic Pain Management from the Closed Claims Project. ASA Newsletter Feb. 2004:68:25-36.

Now what many of us had suspected, from an article titled “Clinical Lessons in Chronic Pain Management from the Closed Claims Project”, by authors K.B. Domino MD and DR Fitzgibbon MD that appeared in *ASA Newsletter* Feb. 2004:68:25-36 a most revealing data has been shown.

They mention that: “Epidural steroid injections (plus or minus local anesthetic and/or opioids) accounted for most of the chronic pain management claims (no numbers given). Nerve injury and pneumothorax were the most common adverse outcomes. Half of the nerve injury claims involved spinal cord injuries (primarily paraplegia and quadriplegia) which were associated with epidural steroid injections and other procedures. Pneumothorax was the most common complication from trigger point injections.”. They added that “Epidural steroid injections were associated with significant adverse outcomes (such as death and brain damage) only if local anesthetics and/or opioids were used with steroids. The authors concluded that “epidural steroid injections are not free of risk” and went up to say that “injections in the vicinity of the neuroaxis may on rare occasions result in unintentional serious nerve injury such as paraplegia and quadriplegia. Serious infectious complications (epidural abscess, meningitis, osteomyelitis) also may follow epidural steroid injections”. As advice the authors concluded by saying “Patient safety may be

improved by excluding opioids and typical epidural doses (volumes in excess of intrathecal test doses) of local anesthetics, from epidural steroid injections.

Readers are warned not to consider the information included in this latter review of data by Domino and Fitzgibbon as statistics or incidence of complications are these are only the cases in which malpractice insurance claims were filed. These are not all the cases litigated since only included certain insurance companies, but not all. In addition, it is likely that many more cases were not litigated.

Dietrich CL and Smith CE: Epidural granuloma and intracranial hypotension resulting from cervical epidural steroid injection. *Anesthesiology* 2004;100:445-447.

As a matter of INFORMATION for all those that thought that doing “blind” procedures under fluoroscopy guidance assures that the needle tip will be in the correct place I suggest that you read the article by Dietrich CL and Smith CE: [Epidural granuloma and intracranial hypotension resulting from cervical epidural steroid injection. *Anesthesiology* 2004;100:445-447](#) which describes the formation of a mass in front of the spinal cord and within the lower brain, which in fact was the steroid administered in both compartments, peridural and intrathecal. Although less common, misplacement of needle tips also happens even when fluoroscopy is used, because the dural sac can not be seen by this imaging technique. There is no substitute for experience and careful technique.

A few more (by no means all) references of injury to the neuroaxis from invasive procedures in the spine are listed as follows:

HsiaAW, Isaac K, Katz JS: Cauda equine syndrome from intradiscal electrothermal therapy. *Neurology*:2000;55:320.

Onik GM, Maroon JC, Jackson R: Cauda equina syndrome secondary to an improperly placed Nucleotome probe. *Neurosurgery* 1992;30:412-414.

Epstein NE: Surgically confirmed cauda equina and nerve root injury following percutaneous discectomy at an outside institution: a case report. *J Spin Disord* 1990;3:380-383.

Absalom AR, Martinelli G, Scott NB: Spinal cord injury caused by direct damage by local anesthetic infiltration needle. *Br J Anaesth* 2001;87:512-515.

COMMENTARY

Not wanting to appear completely negative, I am convinced that advances in technology will eventually produce devices that would control every type of pain with minimal or no risk of injuring patients, that would not create dependency and that would be made available at a reasonable cost. I realize that it sounds like a Christmas wish list, but all that can be achieved; if man has gone to the moon, to the depths of the oceans and there are no more remotes unexplored regions in earth, we certainly ought to be able to control pain in the near future.

The incidents herein mention only few of many reports that appear every month in medical journals and should be published to inform the medical profession and

indirectly the public, however what is needed is a comprehensive study of incidents with a guarantee of privacy so we can learn what is the real frequency of complications or failures from laminectomies, spinal fusions, epidural steroid injections, adhesiolysis, trigger points, etc, etc. I recognize that from our own publications these sweeping conclusions can not and should not be reached. Thus far the Institute of Medicine has launched studies trying to define the causes of deaths occurring in American hospitals from adverse events. We can only assume that there are by far more complications not necessarily causing deaths that need to be defined, too.

EPIDURAL STEROIDS

Bogduk N: Current Guidelines in the Use of Epidural Steroids: Reports from Australia, Belgium, Norway, The Netherlands, the United Kingdom, and the United States of America. Pain Digest 1999;9:226-234. Next page contains a scanned copy of this report.

Guidel

Current Guidelines in the Use of Epidural Steroids: Reports from Australia, Belgium, Norway, The Netherlands, the United Kingdom, and the United States of America

Epidural Steroids for Low Back Pain and Sciatica: Executive Summary and Recommendations of the Working Party of the National Health and Medical Research Council

N. Bogduk, M.D., Ph.D.
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In 1994 a report was published by a Working Party of the National Health and Medical Research Council (NHMRC) about the value of epidural use of steroids in the management of back pain.

The working party was chaired by Professor N. Bogduk. He agreed to publish the executive summary and the recommendations in this issue.

To complete this Australian point of view, we mention certain features that Professor Bogduk wishes to emphasize in the context of this publication.

Executive Sum

1. The term *epidural steroids* refers to the injection of corticosteroids into the epidural space of the vertebral column as a means of treating pain of spinal origin.
2. Steroids can be injected into the lumbar epidural space by way of an interlaminar route (lumbar epidural steroids) or a transsacral route (caudal epidural steroids). In the cervical spine epidural steroids can be delivered by an interlaminar route. Less commonly used is the transforaminal route at lumbar and sacral levels.
3. There is no indication in the literature as to what constitutes a "standard" epidural injection. Different authors have reported the use of different steroids in different doses and with a variety of different adjunct

agents such as normal saline and local anesthetics at different concentrations and in different volumes.

4. Over the past 40 yrs the use of epidural steroids has enjoyed endorsement in the medical literature throughout the world; however,

The endorsement of epidural steroids pertains only to the use of caudal and lumbar epidural injections for radicular pain described as sciatica or in similar terms.

There is only a small body of literature on the use of cervical epidural steroids, which is mixed with respect to favor, enthusiasm, and results; and

There is a minimal body of literature pertaining to the use of epidural steroids for the treatment of any form of spinal pain other than radicular pain.

5. The rationale for the use of lumbar and caudal epidural steroids is the belief that lumbar radicular pain involves an inflammatory process of the affected nerve or its dorsal sleeve; but the evidence for this belief is, at best, circumstantial.
6. A competing theory is that the apparent therapeutic effect of epidural steroids does not arise because of the anti-inflammatory action of the drug but because of its capacity (like a local anesthetic) to block conduction in the spinal nerve, its roots or the nerves that supply the nerve-root sleeve.
7. The chief apparent effect of epidural steroids is to reduce pain but this effect is limited in duration. Although more lasting remissions have been reported, the proportion of patients obtaining relief of pain following a single injection attenuates rapidly, with most receiving good relief for a matter of weeks or for up to 3 mos after the injection, and only a small proportion obtaining longer-lasting relief.
8. Despite its widespread endorsement in the literature, the use of epidural steroids has not been vindicated by double-blind, controlled trials with:
Two controlled studies of caudal epidural steroids that approach, but do not achieve, statistical significance;
One acceptable study of lumbar epidural steroids that denies any benefit in patients with myelographically confirmed nerve-root compression;

INQUIRIES

I need to state that to protect patient's confidentiality under HIPAA, I do not offer medical opinions over the Internet. However, it is not uncommon for our web site to receive inquiries concerning the causes of death in patients with arachnoiditis, or whether this disease leads to an earlier death or not. To my knowledge there are no objective statistics that would answer these questions. Moreover it would be very difficult to come out with a correct answer. Surveys have the weakness of being subjective, not been able to prove what is stated and the limitations brought by prejudice, emotional disturbance, anger and other factors. I can only tell you that I have not seen or heard that a patient dies from ARC. There are some related causes but any discussion about them would be purely speculative. Perhaps in the future some realistic facts can be produced, but in the current atmosphere of confidentiality and liability

CONTRIBUTIONS FROM THE READERSHIP

REFLECTIONS

TREATY

No fanfare,
this treaty I've hammered out,
just injectable gold
liquid and pills.
Multicolored capsules
sometimes,
but generally pills:
hexagonal,
the geometry of relief.

Ardent ambassadors,
doctors insist the treaties
supplying liquid gold
and little pills deliver hope.
They talk to me about hope,
like priests murmuring to condemned
about eternity.
I like to hear them say these things.
But I notice hope
no longer
crosses frontiers of pain.
Just the same,
I want to believe them.

Like all Treaties,
this is commerce:
doctors prescribe and I consume,
and we pretend,

to everyone's benefit,
that this will comfort restless minds.

But like all the rest of us
enveloped in pain
I've had to take control:
I now prefer endurance.
I no longer bargain for
hope. No,
I've accepted a treaty for the simply
tolerable.

It's a good deal,
this treaty between endurance
and tolerable.

Mark Maginn

CALL FOR WRITTEN CONTRIBUTIONS

As in the past, we invite contributions by physicians, patients, relatives of patients, therapists on subject related to ARACHNOIDITIS, specially their impressions, experiences and sacrifices as they help or care for this patients.

CALL FOR DONATIONS TO THE ARACHNOIDITIS FOUNDATION TO CONTINUE TO FUND THE RESEARCH .

To all of you that have communicated with the Arachnoiditis Foundation, Inc. in the past, those of you that we have been advised, informed or help in any other manner it is the time of the year that we ask for your help in the form of donations to this NON FOR PROFIT ORGANIZATION so we can continue to pursue the investigative activities that already have helped us to define the causes of Arachnoiditis, to understand the mechanisms of injury and the phases of progression. We need to find treatment for the early and for the long term phases of this disease.

Be assured that your donations are tax deductible as this is the ONLY Foundation truly authorized as such by the IRS. Any donation, as small as it may be it will be helpful.

ARACHNOIDITIS (ARC) is a disease of the spine that involves the dural sac, spinal cord and nerve roots that starts with acute inflammation and progresses to fibrosis and scarring of these organs. It is usually acquired from infections, trauma or from medically related invasive procedures (spinal surgery, injections, myelograms spinal anesthesia and others). Hundreds of thousands of individuals are affected by this disease; many do not even know that they have it, because the diagnosis has not

been made. Thanks to the information dispersed by the Foundation more doctors are now becoming familiar with the symptoms and the diagnosis of ARC. More importantly by publication in medical journals, lectures and scientific exhibits at scientific meetings, plus the initiation of our quarterly “ARC Newsletter” we have raised the awareness of the fact that ARC can be initiated by incidental happenings during invasive diagnostic, pain management and surgical procedures on the spine suggesting that the risk/ benefit ratio of every interventional treatment needs to be re-evaluated.

By conducting basic research, an animal model for the study of arachnoiditis, that will allow us to investigate every substance that may possibly cause it, but more importantly, in the near future different medications can be tried to define a possible cure. Not that we want to give false hopes, but persistence and determination usually reward good science. When would such reward come? We do not dare to predict. In addition, our clinical observations have allowed us to identify if the causative agent was a needle trauma or an irritant substance, vs. a spinal operation. Four different very complimentary reviews of the book “ARACHNOIDITIS; THE SILENT EPIDEMIC” were published in American, British and Asian journals. This book has now been made available to patients at the reduced cost of 25.00 US dlls for patients with this disease. The book continues to be in such demand that soft cover volumes were reprinted.

The **ARACHNOIDITIS FOUNDATION, Inc** is a non-profit organization founded and dedicated for the purpose to:

- a) Disseminate awareness about ARACHNOIDITIS, the severe constant pain that it causes, the dysfunction it produces in certain organs and its chronic disabling and debilitating nature.
- b) Make available information about how to prevent, diagnose and treat ARACHNOIDITIS to medical doctors, nurses, therapists, allied professionals, health maintenance organizations, authorities, governmental health care agencies and the public in general.
- c) Request GIFTS, DONATIONS and GRANTS from patients, health professionals, legal professionals, drug and equipment manufacturers, private charities and the public in general.
- d) Fund basic and clinical research on the causes, the diagnosis and the treatment of ARACHNOIDITIS.
- e) Provide scholarships, seed grant monies, organize and support meetings and to present conferences that would foster, stimulate or advance the understanding and knowledge about ARACHNOIDITIS.

As you can see the objectives of the **ARACHNOIDITIS FOUNDATION, Inc.** are many and they are challenging, nevertheless all of us are determined to solve them. We cannot accomplish this alone, so we are asking for your help and support in this monumental task.

J. Antonio Aldrete, MD, MS

Founder and President

For more information visit our WEB SITE www.arachnoiditis.com , read the issues of our ARACHNOIDITIS NEWSLETTER, or contact me at my e-mail aldrete@arachnoiditis.com

Your tax deductible contribution to the Arachnoiditis Foundation, Inc. will allow us to learn more about arachnoiditis so we can eventually prevent it and treat it.

**CALL FOR LETTERS, ARTICLES,
CONFESSIONS POEMS, DEBATES, etc.**

Readers are invited to write short, but meaningful, articles on any subject related to Arachnoiditis. They may be submitted with the author's name or anonymously, however, with the understanding that:

- a. The Editorial Board reserves the right to modify them or alter them to conform with the style and the "Objectives" of the ARC Newsletter.
- b. The copyrights will be waived with the assurances that the Editorial Board will not derive any profit from any of these publications.
- c. They are simple, constructive and civil.

Thank you.
The Editorial Board

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