



ARC (ARACHNOIDITIS) NEWSLETTER

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EDITOR'S PAGE

On my way to Europe, during the flight over the Atlantic Ocean, I still experience the same thrill and anticipation that I had nearly 35 years ago, when I first came to visit, the "old continent" in spite of the strained relations, it still elicits that aura of mysticism and admiration that I had then. Twenty six years after the II World War, the Reims cathedral had not been totally restored, there were still bunkers in the Champagne region, Franco kept a tight rein on Spain and crossing to East Berlin required going through "Check Point Charlie". I noticed that the apartments in communist Germany then, resembled those that I saw in my first visit to Beijing in 1985 and amazingly, they look very similar to those that I saw in La Havana when I visited in 2003. It is a chronological sequence that has evolved during the last half-century. I wonder whether the battles of ideology are worth the sacrifice of those people cut in the midst of someone trying to prove some sociological theory or show that one way of life is better than another. There is no doubt that, with few exceptions, most people are better off; as they progress in to an open, more free sociological, religious and political society that eventually leads to a more financially stable set of circumstances. At any rate, what and who help to make those changes possible seem to have been forgotten.

Though the socialistic democracies in Western Europe and Scandinavia have had some sort of free or almost-completely free health care for their inhabitants, lately there are symptoms that not-all-is well in these systems that provide free or near free medical care. I do not consider myself an expert on international health organizations, but I spent sabbaticals in Sweden and in The Netherlands, have visited extensively most other countries and have close relations with many prominent physicians in those countries; so my impressions have certain basic personal experience and information. I know that in France doctors went on strike several times in the last two years because they feel over worked and underpaid, though 34 hours/week does not seem excessive. In Holland patients are been asked for small co-pays which most people have protested against, but there has been discussions about limiting some services. From reviewing a number of cases from the UK it is evident that patients are unhappy, with the National Health System, so are the doctors, but the attitude of contempt exhibited by the personnel and the run-around that the patients receive

when seeking appropriate care is incredible; patients have little chance to complain, and the medical disasters are common to ours and other systems. From my time in Sweden, I believed that their health care system was the best, patients received completely free medical care and medications, they pay high taxes for it; there are limitations and long waiting periods for chronic conditions, but the quality is very good. All doctors receive the same salary so they do not have the incentive to operate more, to endoscope more or to test more as their salary will be the same. One may say, well they do not have motivation, which may be true; on the other hand there is not the strong indication as when the patients have “good” insurance; then, the diagnosis is made to fit the indication, as it happens sometimes in the USA, where doctors have found out that fitting the diagnosis to the treatment is one way that the insurance companies pay (most of the time) so not uncommonly a great deal of subterfuge and machination go into creating a diagnosis that will correspond to a procedure that pays well. So as they say, all is about money.

Among all other political and social problems we have in the USA is the availability of giving health care to the whole population; there are 41 million Americans that do not have health insurance; another frightening fact is that 60 other millions are underinsured, that is their policies are so unfavorable to the patients, with such high deductibles and low benefits that they do not go to the doctor, or do not buy certain expensive medicines because of the high co-pay. Another large group, probably 55 million, of which no one talks about is that by making health insurance work-dependant, their coverage is at the will of their employer; if one worker has a child with a frequent need for doctors visits, hospitalizations or expensive medicines, he or she may lose their jobs, which means, lose their health insurance. Under those circumstances, who can afford COBRA when one does not have a job? In the last few months several of my patients that require long term pain management have been fired from their jobs for questionable reasons; some lost their jobs after working for their companies for over 25 years, as they approached retirement. The truth is that this kind of coverage held by blue-collar and kaki-collar workers, is tenuous, when the bosses are squeezed, the first thing to go are the employees whose families require a lot of medical care related expenses. There must be a better way.

There is no doubt in patients and doctors minds that managed care is not a solution; except for the insurance companies top employees and the CEO's of the large “health plan systems” everyone is having a hard time, the prices for hospitalization have “gone through the roof” and the medications are unjustifiable too expensive. So what is next?

For decades, it has been my impression that improvements in technology in medicine and the questionable advancements in pharmacy products have gone further and grown faster than any budget (government or private) can afford. There is no way to keep paying for all the new medications, imaging studies, stem cell research, spinal fusions and genetic medicine as the demands run rampant, while millions are dying of plain gastroenteritis, undernourishment or environmental trespasses. Some hard

decisions will have to be made to decide what is best for more and not to spend a lot to save a few. I am glad I am not making those determinations.

ON VIOXX AND HOW THE FDA APPROVES OR DISAPPROVES DRUGS

The latest fiasco on the approval, disapproval of this medication has prompted some inquiry that thus far has revealed some frightening facts. Five years ago, when Celebrex and Vioxx were approved to use as anti-inflammatories, they were announced by their respective manufacturers as great advances in pharmacy since they acted specifically in the enzyme Cox 2 and supposedly had minimal or no undesirable gastrointestinal side effects. At the time it had been announced that 20 000 hospital admissions were caused by gastric bleeding produced by the “old” drugs. What an improvement ???

Since then we have found that these two new products do produce gastritis and stomach ulcers requiring frequent gastroscopies and when some scientists thought that Vioxx may reduced the incidence of colon polyps and cancer they initiated a large population study to support those findings. At about 1999, I was asked to review the laboratory findings and to give a lecture on it; when I reviewed the studies, the evidence appeared to me doubtful and there was lack of scientific support. I went to the meeting and stated my impression. The manufacturer’s reps were unhappy, I never received my honorary, but I left it as it was, since I believe no harm was done, but I gave my opinion.

Based on questionable observations, Merck and Co. decided to pursue an indication for the prevention of colon cancer, different from what they had already for pain due to arthritis; the regulatory agency FDA partly funded an expensive study that reviewed over 1.3 million medical records of “subscribers” to the Kaiser Permanente health care system, of which about 40 000 received Pfizer’s drug Celebrex, and compared them to nearly 27 000 patients given high doses of rofecoxib (Vioxx); the last group was found to have a triple risk of myocardial infarction, stroke and sudden death. Interestingly enough, one of the FDA associate directors for science in-charge of monitoring the study Dr. David J Graham had raised questions during the early stages of the on going study. Subsequently, he was subjected to threats and isolation because he had expressed doubts about the safety of the study. Within the agency he became a pariah, because he had dared to raise a “red flag” about a medication for which the FDA itself was sponsoring the research study. This finding raised the question of why should the taxpayers monies be used to pay for helping one of the drug manufacturers to prove a secondary indication for a medication that has already been approved, by the FDA for a primary indication?

Dr. Graham’s supervisors resisted his efforts to warn the doctors and the public insisting that he “soften” his announcement. Eventually the evidence was so overwhelming that they allowed him to issue a soft warning indicating that “these medications should be taken with caution”. Patients are having fatal complications, for goodness sake why be shy about it?

Another similar series of events went on when Dr. Arnold Mosholder, an FDA epidemiologist informed his supervisors that children taking antidepressants had a higher incidence of suicides, suggesting a preferential use of Prozac. Again, his supervisors instructed him that he “should put a warning that would suggest that children use such medications with caution”. The acting Director of the FDA’s Office of Drug Safety denied that Mosholder was pressured to soften the warning. There is no question that depressed patients may consider suicide at some times, but when certain drugs may increase that possibility, they should not be prescribed to them.

There we go again, here is the regulatory federal agency that should oversee the drug manufacturing industry, acting as a “softy” and punishing their own investigators for doing their job. After these incidents, “who can we trust to protect us”.

For those of you, patients with ARC that were taken Vioxx, other options such as Feldene, Indomethacin, Bacitra, Celebrex. may be considered; it has been suggested to alternate 3 or 4 different medications (as they all act similarly) so as to reduce their side effects. Ask your physician for guidance.

From looking at Merck’s stock, it seems that it would have been better of staying with Vioxx only as anti-inflammatory and explore other applications for their drug indomethacin. At any rate, one never knows what drives such decisions.

WHAT ABOUT FLU VACCINES?

As winter approaches, suddenly the American public was informed that the so called “flu” vaccine that most elderly individuals, children, and patients with critical illnesses, as well as, veterans supposed to have received this fall, might not be enough to go around. Evidently, a US owned company, Chiron, with offices and laboratories located in England had its license suspended three weeks ago. This outfit is owned by a biotech company from Emeryville, California that trades in the NYSE; this fact has allowed the Securities and Exchange Commission to investigate this firm; so far it has received a subpoena from the U.S. Attorney’s Office in Manhattan.

The FDA had conducted a campaign to convince most Americans to receive the flu vaccine so as to avoid deaths in the winter time; suddenly after explaining how important it is to receive it, now it has to choose who is going to receive the few lots that will be made available. This has produced some panic among the potential candidates to get it. After having made themselves to believe that they should receive the vaccine, as the best way to prevent the flu this winter, now most of those previously considered candidates are not going to receive it. WHAT A FIASCO.

To place this problem in the proper context, one has to understand how the decision to choose what viruses, this year’s flu vaccine is supposed to prevent, is made. As there are dozens of “flu viruses” that may infect any one individual, any one of them may become the prevalent virus affecting one specific patient. They also vary from patient to patient; so how can a vaccine be made in anticipation of an epidemic when

no one really knows, for sure, what virus, specifically is going to infect one specific person, next winter?

As it happens, the process goes something like this, a group of virologists keep record of what virus were prevalent in the last 10 or 12 winters; they figure that either some patients survived the viremia and have developed immunity; in addition, from previous experience, they know that other strain(s) will be the infectious virus the coming winter. But, as to which one(s) will be the culprit, is not precisely known. Any how, in the spring, they start developing a new vaccine against flu viruses that they have a hint or anticipate will be the prevalent infectious virus, the coming winter. The fact is that they do not know exactly which one it will be. Although vaccines are made against several strains, they can not be made against all strains, so it is a guessing game. WOW.

For those intrigued about this whole saga you may inquire how these vaccines are made and whether the serum of other animals is used to grow the attenuated viruses in chicken eggs to make this vaccine; after a complicated processing the product is inoculated into individuals supposedly at risk and lately it was suggested to the whole population. In some rare instances, other animal species' diseases may be transmitted through this mechanism. Among other conditions, autism was not known until vaccinations were made mandatory for all children.

Some time ago an extraordinary scientist, Linus Pauling, a Molecular Biologist who was recipient of the 1954 Noble Prize for Chemistry and the 1962 Nobel Peace Prize in his professional carrier, published the result of his investigations about "Vitamin C and the Common Cold"; he concluded his findings recommending that taking 5 to 10 grams/day of Vitamin C not only prevented, but also protected against the flu virus and probably against some cancers and other illnesses. For those interested and those left out without vaccination you may find solace and comfort in reading Pauling's book "How to live Longer and Feel Better" (Avon Books, New York, 1987) . I for one follow his advice, have never taken the vaccine and plan not to do it.

As a disclaimer, the author makes these facts known to the readership only as information and not as advice.

THE FAILED BACK SURGERY SYNDROME

We are all hearing more about this condition and it seems pertinent that it should be discussed in this web page, as more and more patients with Arachnoiditis are given this diagnosis and left in the dark as to what it means, what it represents and the significance for their spinal condition.

Failed Back Syndrome (FBSS) implies more than what it says; it is usually assigned to patients that have been submitted to one or more spinal surgical operations and in some cases, to other procedures such as steroid epidural injections, discograms, myelograms, facet joint injections and other interventions, within and around the

spine. At the end, the patient's condition is worse than when they first sought medical attention for their back pain.

It seems that this diagnosis is assigned to a patient when the treating physician feels that there is nothing that can be surgically done for them. Then they are referred to a pain clinic, a psychologist or a physiatrist for more physical therapy. Neurosurgeon Wilkinson who, by now, has published the second edition of his book "Failed Back Surgery Syndrome" honestly accepts that it usually represents that surgical treatment(s) for spinal condition has failed to correct it. The fact is that in the majority of the cases, patients seek medical attention for their spinal condition because of annoying low back pain as the predominant, leading symptom. In other words, they want the cause of their pain gone. If at the end of the process the patient has the same pain, worse pain and/or more side effects like numbness, weakness, headaches and physical disability, the truth is that the original and subsequent procedures have failed to alleviate the patient's chief complain.

As possible causes of the FBSS, Wilkinson listed the following:

- The wrong diagnosis
- The wrong operation
- Operations done at the wrong level
- Careless surgical technique

Among the wrong diagnosis it may be consider

- too small of a herniation, without true radiculopathy (pain down the thigh and leg, numbness and weakness).
- Operating in bulging or protruding discs, centrally located, without radiculopathy.
- Operating in a metastatic lesion lodged in the spine.
- Pre-existent ominous, congenital conditions such as short pedicles, spinal stenosis, lumbarization of the S₁ vertebra or sacralization of L₅ have all have shown to be complicating factors that would most likely will result in need if further surgery with disappointing results.
- Doing a laminectomy alone when there are signs of spinal instability in a patient that clearly needs a spinal fusion or vice versa.

Operating at the wrong level will leave the patient with the same symptoms, this is usually prevented by confirming the contemplated site of surgery by taking an X-ray during surgery while placing a metal marker (usually a hemostat). Occasionally fluoroscopy can be used to make certain that the disc operated corresponds to the radiological images. Operating the correct side is necessary when at discography a right sided tear of the annulus fibrosus can be seen that would be impossible to approach from the left side.

In Spinal Surgery, meticulous surgical technique is essential as the neural structures (spinal nerve roots, rootlets and the spinal ligaments) are extremely delicate, easily torn and do not give to even the gentlest of traction. Tears of the dural sac are

ominous as there may be leakage of cerebrospinal fluid (CSF)s, going out through the incision or forming what is called a pseudomeningocele, which is essentially a false sac into which cavity sometimes the nerve roots go in making it rather painful, sometimes accompanied by electric-like shock pains. These pouches are very difficult to repair and frequently re-appear. Frequently, these pseudo-sacs extend outside the vertebral canal, therefore, any slight blow or pressure is felt as enormous pain, since the bone protection (spinous process and laminae) have been removed.

Adverse events (dural puncture, paraesthesia, nerve root or spinal cord puncture) may occur during some of the pain-relief procedures, complicating an already problematic situation. Arachnoiditis might have been caused at the time of surgery, but if an MRI (with contrast) is not obtained, the later recognition of ARC, is blamed on the secondary procedure. It is essential that in case of an adverse, unexpected outcome occurs after any invasive procedure or operation, an imaging study is performed not only to identify the precise diagnosis, but also to define what procedure caused it. If this is noted after a fusion with hardware (not titanium), MRI's are contraindicated; this will be the only indication for a myelogram (with water soluble dye) followed by a CAT scan.

Epidural fibrosis at the site of surgery and surrounding tissues usually occurs after all laminectomies and fusions, the degree and location depending on the meticulous surgical technique and the procedure performed. If bleeding continues after closure of the wound, as well as, if large clots formed after closure, or foreign bodies (Gelfoam, Adcom-L, thrombin glues, gauze, etc.) are left in the vertebral canal, fibrosis and scarring will most likely develop. This scar tissue may surround a nerve root as it exits the dural sac, to the point that it constricts it, given rise to radiculopathy type of symptoms (pain, numbness, weakness) following the corresponding dermatome (an area of skin, in this case on one lower extremity following the area innervated by the affected nerve root) which is more commonly one of the three nerve roots that form the sciatic nerve. Attempts to remove fibrosis and adhesions surgically are prone to cause direct nerve root injury or dural rents and is also followed by the development of even more scarring. Thus far, any glue, medication or powder designed to reduce scarring has failed and some have actually formed more fibrosis. Similarly, efforts to separate the nerve roots from the adhesive fibrosis using chemical substances failed frequently and may occasionally produce arachnoiditis as the semi-rigid catheter used for these procedures tends to perforate the dural sac more easily than brake adhesions. It is estimated that all these changes happen in 20 to 30% of all the patients that have laminectomies and 30 to 60% in those that undergo spinal fusions. On this issue, Deyo et al (N Eng J Med 2004:350:722) have pleaded for restraint as his collaborators have found that patients operated for fusions had a misdiagnosis in 60% of cases, requiring more surgeries like a 2nd fusion, removal of hardware and disability than those not operated on. Needless to say those that are making the money are the manufacturers of the hardware and the hospitals. The final incentive that could improve the results of this trend will be to change the principle of "evidence-based medicine" (Merril DG: Reg Anesth Pain Med 2003:28:547) to a more realistic

“RESULTS BASED MEDICINE”, in other words, IF THE OPERATION DOES NOT RELIEF THE PAIN , the surgeon should not get paid.

This may appear to be a drastic proposal, but all of us know that it would change the results and would unquestionably reduce the costs.

It must be made clear than it is not the patient’s back that failed to get better, but that the treatment plan decided by the medical care team failed to improve the spinal condition of the patient. It is also pertinent to point out that patients present themselves to the doctors’ offices complaining of back pain and or leg pain; if whatever therapeutic modality is given to them, whether surgery, nerve blocks, epidural injections or physical therapy is prescribed for them fails to relief their pain, then the treatment failed. This is probably more relevant in vertebral fusions, with or without hardware, if pain continues or it becomes worse, even when the fusion is complete, the fusion has failed to relief the main complain of the patient, PAIN.

DIAGNOSIS OF FBSS

This term is indeed a sad cop-out because it does not describe what truly is the diagnosis of the patient. Rather than having to stipulate, that the disc has herniated again, that a loose fragment of disc was left behind, that the fusion did not heal or that fibrosis formed around a nerve root at the operated site, the treating surgeon puts a generic label on the patient that does not stipulate what failed to be corrected or what complication is present; in stead FBSS is a generic enough diagnosis that implies that the patient did not get well, as it would be the patient’s fault. On the other hand having the label of FBSS not uncommonly is seen as “there is no hope for this patient”, or this patient will never get better”. Some specialists do not even bother to see these patients and they are relegated to pain clinics, physiotherapy, alternative medicine, all of which are only palliative, may exacerbate the arachnoiditis (invasive and intervencionist procedures) may be dangerous and tend to drain the patients hopes and resources.

SURGERY AND STEM CELL RESEARCH IN ALS

Amytrophic Lateral Sclerosis (Lou Gehring’s disease) affects the motor neurons producing gradual paralysis and eventually death in four to seven years. Patients affected by this disease gradually loose the strength of the muscle of the extremities and eventually the respiratory muscles, requiring ventilator assistance. An experimental model has been created in mice grown genetically targeted with this disease so studies can be done trying to evaluate diagnostic methods and treatments. Out of the blue, we began to receive news that in Beijin, China Dr. Hongyung Huang a Chinese neurosurgeon had performed a number of implantation of grown stem cells into the brain of patients with ALS with apparently early improvement of the muscle strength of the larynx and respiratory muscles. The procedure goes like this patients contact the Chinese hospital where Dr. Huang works and for 20,000 dlls, they are put on the list; they travel to Beijin where they are placed in a facility close to the hospital.

Dr. Huang apparently had worked earlier in Rutgers University in the USA. Apparently fetal stem cells are readily available in China as they have the policy of having one child only. In a simplistic explanation, fetal cells are taken from the olfactory bulbs of 3 to 6 months old fetuses, they are grown in special ovens and then after 3 to weeks they are injected into the brain to regenerate or stimulate the growth of more motor neurons. Some hopeful comments have been made by American scientists while others have been critical of the fact that patients are being operated without demonstrating that treatment will be effective. Dr. Huang apparently has responded that the USA is falling behind in stem cell research due to the government ban on it. When asked about prior studies in animals he indicated that studies in special mice will be started next month. The latest report in a Dutch newspaper indicated that six patients have died weeks after surgery.

Some skepticals reminded the public that in the 70's snake venom was touted as cure for ALS and patients flocked to Florida where clinics were improvised only to be debunked as more and more patients were treated with no satisfactory results. Apparently some subtle improvements were explained as "the power of human hope and intense belief".

Patients are cautioned not to read much into these findings; though we encourage any attempt to show improvement as long as it does not have the possibility of causing harm.

Taken from the Mobile Register, October 19, 2004.

Arachnoiditis has a different cause, over 90% of cases are caused by interventions or operations in the spine; information needs to be spread that the majority of these procedures do not improve significantly the spinal conditions. Laminectomies and discectomies may take the pain temporarily but it will come back within few months, then further surgery will be more hazardous and less likely to have an optimal outcome. It has been shown that Americans are operated with spinal fusions 8 to 10 times more often than most European countries it is obvious that we should follow Deyo's advice and only have these surgeries or invasive pain-related procedures when they are definitely and absolutely indicated.

CHIPPING THE BLOCK LITTLE, BY LITTLE

Believe it or not, but we are gradually succeeding in informing patients, doctors and authorities of the potential dangers that may occur when these procedures are done incorrectly. Unfortunately this happen more often that we are willing to admit. One recently published article in *ANESTHESIOLOGY*, October 2004, on the incidence of neurological complications of spinal and epidural anesthesia has some misconstrued statistics with low frequency of complications but when one looks into the methodology on how they obtained their information, any one (but the editors) can see why. The authors wrote to the Chiefs of Anesthesia asking them to give them information on the numbers of complicated cases (by memory). Naturally this

retrospective, not comparative, study showed a very low incidence of complications. There is another article in *ANESTHESIA AND ANALGESIA* December 2003, from doctors in the Mayo Clinic who label their paper “Small Danger for continuous Lumbar Epidural Anesthesia in patients undergoing major Upper Abdominal and Thoracic Surgery”, they retrospectively found 6 complications in over 4000 patients only by looking into the Neurology consults obtained in that number of patients. Knowing the patient population in this famous center of medical care where 90% of the patients come from somewhere else, the statistics obtained three years later just from another service (Neurology) consults leaves a great deal to be desired. In addition, as these middle age and older patients having major surgery of the chest and abdomen went home and were followed by their local doctors, minor or major neurological deficits may or may not be detected as they probably had some other major medical problems, perhaps perineal numbness, a drop foot, burning pain in the feet may go undetected. Moreover, bladder or bowel dysfunction might have been attributed to the surgery or the patients serious illness(es). So in my opinion there is still not a realistic dependable statistic that would sustain a meta analysis.

Nevertheless, from our lectures, exhibits at meetings, letters to the editors, articles and chapters in books the message is being delivered and someone is listening to it. Questions, inquiries and contacts made by colleagues describing complicated cases are on the rise. As we pleasantly observed during the October 2004 yearly ASA meeting, held in Las Vegas, there was a vast interest on the subject from the colleagues attending. We received very positive comments whereas before physicians disregarded the subject as either “non-existent”, “never seen in their practice”, “heard about it, but it doesn’t happen anymore because we stopped using pantopaque”. We are very happy to inform you that now the attendees of these meetings come to look for our exhibit, remember us from previous meetings and want to obtain the latest information on arachnoiditis. They want to discuss what can be done to prevent it and obtain advice on what to do if it occurs in their practice. Reactions to our exhibits have been very positive, finally, doctors are listening and this is a step forward in our cause because if they hear us, they will also hear their patients.

QUESTIONS, QUESTIONS, QUESTIONS

I have received many questions from patients concerning impending procedures that have been proposed to them, but I need to state that to protect patient's confidentiality under HIPAA, I do not offer medical opinions over the Internet. Laws in many states prohibit physicians from giving medical opinions or advise over the Internet to a person with whom the physician does not have an established doctor-patient relationship. Giving medical advise over the internet to a patient who's medical records I have never seen, who has not been personally examined by me, is in my opinion not only unethical but extremely unfair to the patient who will be only getting a guesstimate opinion. As far as my answer to inquiries I can only answer them in a generic form.

About "Epidural Blood Patches" they are indicated to treat the persistent headache that is created by the perforation of the dural sac with needles, allowing leakage of the cerebrospinal fluid (CSF). This produces severe head ache that gets better when the patients lie down and gets worse when they sit up or stand up. They occur rarely when spinal anesthesia is used, because the needles have a smaller caliber. The headaches are more frequent, more severe and more difficult to treat after an epidural anesthetic is used, because the needles are by far larger and the hole made in the dura is also larger. It is recommended that patients are treated conservatively with large amount of fluids, caffeine, bed rest and others. If it persists the injection of blood may be considered; however the blood has to be injected in the epidural space, requiring another puncture which may also perforate the dura. If successfully injected into the epidural space, enough blood has to go through the hole to form a plug. If too much blood passes into the compartment of the CSF, it may inflamed the arachnoid layers. It usually stops the headache, but it has a 10% failure and a certain risk.

Has any one have had a discogram and was told that he/she does not need surgery? This is supposed to be a diagnostic procedure, which is used to justify certain operations when the diagnosis is doubtful. It consists of injecting a dye (1.0 to 1.5 ml) into the core (nucleus pulposus) of the disc; the cavity is so small that if 2.0ml of dye are injected it produces pain, it produces pain on everybody, so when the patient experiences this pain that resembles the pain from herniated disc, doctors say that is where you have a lesion and you need to have surgery. In other words, "provoking discography" can be manipulated at will to elicit pain, depending on how much volume of dye is injected. They are always positive and most patients usually end up on the operating table. The cost of the discography is added to the cost of the surgery. Who needs this?

Most information is obtained in an MRI which is an excellent diagnostic tool if technically executed well and if it is interpreted and read carefully by a competent and diligent radiologist. What you must demand is to have a comprehensive interpretation by a competent radiologist that would read the films and report space by space, describing the condition and the location of the bones, the ligaments, the discs, the nerve roots, the spinal cord, the cauda equina, if there are short pedicles, vestigial discs, cysts, which is the optima epidural space. After surgery the MRI should be done with contrast, do not accept "surgical changes" as an interpretation, you and your doctor need to know in detail what is going on. The radiologist has the obligation to be informative explicit and to describe carefully everything that is present in the films, regardless of what your age is, after all some one has gotten paid 1500 dlls for it. Some radiology groups used locum tenant radiologists that are one day here, tomorrow somewhere else, they are not interested in doing a good job, just to dictate as little as possible, so they do not acquire liability. Who loses with this arrangement? is the patient because important information is not passed to the doctor who ordered the study and the proper and complete diagnosis is missed. Ask to have a full description, where the scarring is located? How extensive is it? does it surround nerve roots?, are there cysts?, foreign bodies?, displacement or deformity of the dural sac by fibrosis?, are the nerve roots clumped, at what level are they clumped or

“enhanced”? Are there loose fragments of disc, vertebral compressed fractures?, spinal stenosis?, is there epidural space where surgery was done?, are the facet joint overgrown (arthritis)?etc, etc. Ask for a detail report that should be at least one page, do not accept three or four lines, after all, many doctors do not know how to read this films and go strictly on what the radiologist dictates. Do not be shy, your doctor needs all the help that he/she can get and all the information that the radiologist can give him/her.

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.

LECTURES AND PRESENTATIONS IN 2003 BY DR. J. ANTONIO ALDRETE

“Cefalea postpunción.” VI Curso Regional de Anestesiología region VI, Colegio de Anestesiólogos de León, León, Mexico, January 24, 2004.

“Síndrome transitorio de raíces nerviosas.” VI Curso Regional de Anestesiología region VI, Colegio de Anestesiólogos de León, León, Mexico, January 24, 2004

“Diagnóstico y manejo de la Aracnoiditis postpunción.” X curso del Noroeste y IV Interacional de Temas Selectos en Anestesiología, Universidad Autonoma de Sinaloa, Mazatlán, México, March 6, 2004.

“Beware of dural sac anomalies and abnormalities.” 13th World Congress of Anaesthesiologists, Paris, France, April 19-22, 2004.

“Pain generators in patients with failed back syndrome.” 13th World Congress of Anaesthesiologists, Paris, France, April 19-22, 2004.

“Epidural steroids vs paravertebral nsaid’s + reduced steroids on outcomes inpatients with failed back syndrome.” 13th World Congress of Anaesthesiologists, Paris, France, April 19-22, 2004.

“Outcome differences between lumbar. caudal, transforaminal or paravertebral injections of steroids for HNP and FBS.” 13th World Congress of Anaesthesiologists, Paris, France, April 19-22, 2004.

“Lack of neurotoxicity from chronic intrathecal infusion of indomethacin in guinea pigs.” 13th World Congress of Anaesthesiologists, Paris, France, April 19-22, 2004.

“Nerve Root Regeneration.” 13th World Congress of Anaesthesiologists, Paris, France, April 19-22, 2004.

Open Forum “Estudio de una quimera: Aracnoiditis, de la ficción a la realidad.” 1º Jornada Internacional de Educacion en Anestesia “Dr. Jorge Antonio Aldrete”, Universidad Catolica de Santiago de Guayaquil, Guayaquil, Ecuador, May 14 – 15, 2004.

“Cefalalgia post-punción dural.” Primeras Jornadas Rosarinas de Anestesia en Cirugía Ambulatoria, Fundación Anestesiológica de Rosario, Rosario, Argentina, May 25, 2004.

“Deficits neurológico y aracnoiditis pos anestesia neuroaxial.” Primeras Jornadas Rosarinas de Anestesia en Cirugía Ambulatoria, Fundación Anestesiológica de Rosario, Rosario, Argentina, May 25, 2004.

Interviewed for the “Living History of Anesthesiology” sponsored by the Word Library-Museum of Anesthesiology, ASA Annual Meeting, Diamond 1 Room, Las Vegas Convention Center, Las Vegas, Nevada, October 24, 2004, 1:00 pm-2:30 pm.

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*Merry Christmas and best wishes
for a happy, healthy and peaceful 2005*

*HAPPY HOLIDAYS
From the ARACHNOIDITIS FOUNDATION, INC.*

**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 dls 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.

YOUR KIND AND GENEROUS DONATION (tax deductible) in the form of \$25.00 ____, \$50.00 ____, \$75.00 ____, \$100.00 ____, 1000.00 or more _____ would be greatly appreciated. I can assure you that it will be destined and dedicated in its entirety to the fulfillment of the Foundation’s objectives (as we have no administrative expenses).

As a token of appreciation for your support, the FOUNDATION will send you a copy of the book “Arachnoiditis: the silent epidemic”. If you already have it, you may donate it to the medical library of your choice. On behalf of the ARACHNOIDITIS FOUNDATION and of the many patients that will benefit from your gift, I wish to express our most sincere gratitude. Have a Happy Holiday Season.

J. Antonio Aldrete, MD, MS
Founder and President

The hopes of many patients suffering from Arachnoiditis are perhaps better expressed in this pyramid of phrases that my patients have shared with me, a confidence that I have treasured for their meaning and sentiment:

*

Get back my life.
Walk beyond the mailbox.
Not be depressed and lonely.
To have sex without pain. Not sweat all the time.
Be able to go back to work. Get out of bed feeling normal.
Get off from all these medicines. Play with my kids as I used to.
Hope for something good for a change. Be able to pick up and carry my grandchildren.
Not to be embarrassed by my bladder malfunctioning. Have a three day holiday without pain.
Be able to walk through a shopping mall and enjoy it. Sleep a whole night and wake up without hurting.

Let's continue to work so we can change this despair and hopelessness.

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.

J. Antonio Aldrete, MD, MS
Founder and President

**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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YOUR DONATION WILL HELP TO LEARN MORE ABOUT ARACHNOIDITIS