



ARC (ARACHNOIDITIS) NEWSLETTER

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2001 THE YEAR OF THE BEGINNING OF A NEW CENTURY

Realizing that information is an ongoing process, the **ARACHNOIDITIS FOUNDATION, Inc.** Board of Directors has decided to further the dissemination of knowledge on this dreadful disease by initiating a bi-monthly newsletter that will keep visitors to the

www.arachnoiditis.com web site advised of the current developments in the ever growing conglomerate of ARC-related events, happenings, debates on procedures, news on diagnostic tests, answers to questions from patients and analysis of any proposed therapeutic agents that may alleviate one or more of the symptoms of ARC sufferers. We plan to discuss objectively controversial issues, warn against hazardous procedures that may cause ARC and announce results of ARC-related research studies with an objective analysis of the same. In this Forum we plan to gain greater insight into the indications of certain medications frequently used by patients with ARC, intent to estimate the odds from procedures proposed to treat some of the spinal disorders that may accompany ARC and to scrutinize the risk/benefit ratios of interventions proposed to relieve the most common, burdensome and destructive symptom, **PAIN**.

ACCOMPLISHMENTS

With this introduction, it is pertinent to let everyone know that it has been a little over a year since the appearance of the first ever published book on ARC entitled "**ARACHNOIDITIS: THE SILENT EPIDEMIC**" in May of the year 2000 edited by J. Antonio Aldrete, M.D.,M.S., printed and distributed by FutureMed, located in Denver. It took awhile for the word to get around, but now the sales are steady; interestingly enough, one can divide the purchasers into thirds: patients, doctors and lawyers; commentaries are left to the readership. Patients have been granted a 20% discount and as of September 2001 that concession will increase to 30% of the price of \$110.00 (shipping and handling included).

An editorial review by the prestigious journal "Anaesthesia and Intensive Care", volume 29, April 2001, page 210, which is published in Australia, but represents all Australasian continent and has a worldwide distribution. The review concisely stated, "*if you are not familiar with this condition, it is an inflammatory process that affects the supporting tissues of the spinal cord and nerve roots. When progressive, it leads to fibrosis within the spinal canal that causes tethering of nerve roots and ultimately leads to chronic pain, loss of function and disability. Its cause is primarily iatrogenic and can follow spinal surgery, myelography,*

spinal anaesthesia and even epidural blood patch. Symptoms of the condition are often attributed to some other cause. The condition is poorly described in the literature with only a few paragraphs of mention in the bigger anaesthetic and pain management texts.”

Referring to the author, the reviewer noted *“his objective was to write a book that would prove to be a general reference text for all health-care workers involved in managing patients with arachnoiditis. He achieves his goals admirably. Based on research and clinical experience extending over a decade, his book is easily read, despite discussing the subject in great detail and it is extremely well referenced”*. Furthermore, it goes on to say about the contents *“I was impressed by the scope of the book. For example, the chapter on infections has a very topical and relevant section on myeloradiculoneuritis due to AIDS, there was a comprehensive review on the use of local anaesthetic substances in the spine and even the potential hazards of epidural blood patch”*.

The reviewer, Prof. L.A.H. Critchley from the Prince of Wales Hospital in Shatin, Hong Kong concluded *“its contents will be of great interest to all those involved in Pain Management and regional anaesthesia. Having reviewed this book, the reviewer was left with a nagging concern regarding the safety of using spinal anaesthesia in his own practice”*. Obviously, the publication of this book has had a significant impact among the medical community. If nothing else there is curiosity and debate on a number of issues.

RESEARCH ACTIVITIES

A number of ARC-related research efforts are being conducted on several aspects of this disease; one of the projects dealing with the correlation of radiological findings to the apparent cause of ARC was presented by Prof. J. A. Aldrete at the annual meeting of the European Society of Regional Anaesthesia held in Rome on September 17 to 20, 2000. It seems that the extent of radiological lesions seen in patients from chemically produced ARC (i.e. pantopaque) are usually different from those seen after a more localized type of injury like after anesthetic related procedures (spinals, epidurals or blood patches) and both differ from the more extensive and deforming lesions seen after spinal surgical procedures, such as laminectomies, fusions, etc. that usually also include peridural scarring, dural sac deformities and nerve root distortion. This pattern may not be distinctively present in every case as some patients undergo the sequence of myelogram, spinal operation, steroid epidural injection, any of which may be the culprit, making difficult to discern when did the injury occur.

Moral of the Story: have an MRI soon after an untoward event happens following any of these procedures.

Other presentations on various topics related to ARC were done in Poland September 2000

Chiapas, Mexico, November 2000

Guadalajara, Mexico February 2001

Trömso, Norway, June 2001

Other investigational activities currently in progress deal with the complex process of pain transmission that confirms that there is more to Arachnoiditis than “clumped nerve roots”, to mention it briefly, there is a myriad of receptors, transmitters, messengers and other molecular particles and substrates located in a tiny portion of the spinal cord called posterior horn where the perception of touch, temperature and pain arrive. These microscopic structures may be activated, inhibited or blocked by the electrical signals produced by painful stimulation before they are sent to the brain. When chronic, severe pain, like experienced from ARC, goes untreated, it completely alters the function of this delicate system gradually extending to areas nearby thus increasing the intensity and the location of the pain. As we learn more about the functions of these wonderfully designed relay organelles means to modify their actions, sensitivity and what makes them tick have been found implying that either with medications, genetic engineering or tissue modulation, pain may be tamed and hopefully arrested.

That is why declumping alone or separation of the scar tissue, not only does not help but in some cases these maneuvers may make the pain worse. On the other hand changing the cerebrospinal fluid ingredients (proteins, bicarbonate, glucose, lactate and others) it is anticipated that pain transmission may be affected with minimal risk to patients. Although these fact have been known for decades, not until recently, the technique of micro tissue dialysis has allowed to measure continuously these substances in the damaged nerve or brain tissue and its surrounding milieu. Indeed there is hope, that in the near future pain, may be subdued with minimally invasive interventions.

A WORD OF CAUTION

Beware of one sided information; most controversies have two sides to their story. To be able to make a wise decision make sure that you inform yourself about the whole subject; find out what the “pros” say and then listen to the “cons”. More than buying a house or an automobile, making decisions about an operation, an injection or a manipulation may have by far more reaching consequences that may affect your quality of life enormously, most of which are non-reversible. Please seek sound and experienced advice and don’t be shy about getting a second opinion.

Other Sections of this NEWSLETTER in the future may include questions from patients, suggestions, forthcoming events, announcements (anything happening in the immediate or long term future?), contributions by patients, relatives, spouses, health care providers, etc).

Looking forward to hearing from all of you.

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