



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.

SETTING OUR PRIORITIES RIGHT

As busy as we all are, we cannot be complacent allowing the many chores we are obliged to do to take over our intended goal regarding the spread of information on ARACHNOIDITIS.

Since as of today, there is no treatment for it, we then emphasize prevention and that is for Doctors, Patients, other Health Professionals and Insurance Companies to be aware that the incidence of this disease is by far more common than has been considered in the past.

EXPERIMENTAL MODEL OF INTRASPINAL INJECTIONS

At the end of the Newsletter, you may find a list of the Publications (articles, abstracts), presentations, conferences and chapters, mostly (but not all) related to ARACHNOIDITIS, whether directly or tangentially. For those not fully cognizant of medical jargon, it may appear that some of these papers or presentations have nothing to do with ARC, but in fact, they do. For example, together with Dr. Socorro Romero and Dr. Gabriel Guizar-Sahagun, from the Camina Project in Mexico City (an institution dedicated to study spinal cord injuries) we have finally developed the experimental model for arachnoiditis in rats and have presented it at various medical meetings.

Although it was done in rats, injecting phenol, the preparation served as the model to compare to what happens when other substances like normal saline, local anesthetics and steroid dyes are injected into the subarachnoid space. This means that we can compare the effects produced by one of these substances to those of every other medication. We have realized the folly of many studies done previously in animals, is that dosages that appeared to be innocuous to rabbits, dogs, cats and rats are harmful to human's spinal cord and nerve roots. So that is why most other publications that compare the concentrations and volumes that we inject into the spine of men and women do not produce evident injury in animals. So it is not surprising that patients are hurt when some of these procedures go astray (multiple attempts to insert the needle, paraesthesia (electric-shock like sensation experienced by the patient when the needle touches a nerve root or the spinal cord), when dosages or concentrations are too high or when some of these medications are injected in the wrong compartment

but when laboratory studies have been performed those dosages are not enough to reproduce the lesions in animals. You may see in a histological section the proximity of the dura to the arachnoid, the subdural space and the subarachnoid space obtained from a normal rat. These anatomical features are very similar to those noted in humans.

This difference in response has been known for years in the veterinary medicine pharmacology. That means that unless this particular difference is considered, the study was meaningless.

SURGICAL INTERVENTIONS

However, many of you may be surprised that by far the most frequent cause of arachnoiditis are spinal operations, laminectomies and every kind of fusions, specially those performed in the lumbar spine. This may occur from lesions at the time of surgery injury to rootlets (small nerve roots or branches of them) or tear of the dura (the external layer of the sac containing the spinal cord, nerve roots and cerebrospinal fluid); since the patients are usually face down, the dura is at the bottom of the wound; during surgery there is usually constant trickle of blood that accumulates at the bottom of the wound. With a rent of the dura, blood enters the sac and since this is a very irritant substance to neural tissue, it initiates the inflammatory reaction that starts the early phase of arachnoiditis. Failure of these operations is manifested by continuity of the pain that the patient had before or what is worse, a more severe pain with lacerating, burning characteristics. Even when this does not happen, blood that accumulates outside of the dural sac after the closure of the wound, eventually disintegrates and one of the byproducts of this degradation are substances that are highly irritable and can cross the dura, called Cytokines; they are also a highly irritant to nerve tissue and can initiate the early phase of ARC. It is estimated that it occurs in 20% of the cases, but since it is not a desirable term to relate to the surgical procedure, a generic name has been coined to defuse the cause of it. Some of you might have been diagnosed as having "post laminectomy failed back syndrome", which somehow implies that the spine of the patient failed, while in fact it was the operation that failed to relieve the patient's back pain. Patients usually do not choose the operations they want to have their pain relieved. It is our obligation as physicians to propose what in our opinion would be the precise therapeutic modality to relieve the pain. If it fails to relieve the pain then it must be admitted. A second operation has even lower odds to be successful, but has greater chances to produce ARC, as scarring and fibrosis around the dural sac occur after each operation making the dissection more difficult. If a dural tear occurs during the dissection, then blood may enter the sac.

By that time is too late to prevent ARC and those of you who have gone through this sequence of events know that no procedure (epidural steroid, facet joint injections, discectomies, spinal cord stimulators or even intrathecal infusion pump) is going to relieve the pain completely, or for ever. They are just palliative therapies.

So going back to our earlier argument, do inform yourselves well before undergoing any such procedures and make sure that it is understood that what you want and what you need is to alleviate the pain and correct whatever neurological deficit

you may have. You do not need a fusion that heals perfectly well but that does not alleviate the pain.

ABOUT SO CALLED MEDICAL ERRORS

You might have read in one our prior Newsletter of the decision by the mighty Institute of Medicine to study the causes of medical errors in an effort to reduce the 100,000 deaths that occur annually in hospitals to one-half by the year 2005. That is good and dandy, no one opposes such noble intent. But what has not been discussed as yet, is how many patients are not killed (if I may use the word) by medical errors, but just injured and left permanently disabled, or simply damaged for the rest of their lives. We have no numbers, but we can estimate that most likely is six, seven times fold.

Patients with ARC are in this category and until specific statistics are done the incidence of this terrible disease will not be known. I urge all patients groups to communicate with the Institute of Medicine, their local congress men and women to demand that such study is conducted and eventually that measures are taken to reduce and hopefully eliminate these hazards for every patient admitted to hospitals or ambulatory surgery centers.

PAIN FROM DIFFERENT POINTS OF VIEW

For those who suffer pain, regardless of its origin, it is often very difficult to describe it in a precise way.

Perhaps the best definition of pain at present is that of the International Association for the Study of Pain (IASP):

“An unpleasant experience, sensorial and emotional, associated with tissue damage, actual or potential, described in terms of that damage.”

Many have tried to describe, define or explain the sensation of pain, because they have suffered pain themselves or because of their scientific knowledge of pain. These include not only physicians and scientists, but also philosophers, politicians, novelists, essayists, musicians and poets.

These descriptive efforts, full of profound emotion like pain itself, are worth their reading and understanding. Especially by those who have never suffered that unpleasant experience in severe form but that are frequently called upon and are responsible to care for the victims that suffer such terrible condition.

Here are some of these expressions we have encountered in the literature:

"Pain is the cry of nature in distress"

-Anonymous

"Believe the role of the physician is, not only to restore health, but to alleviate pain and suffering"

-Francis Bacon

Essays

"Pain is the weakest point in modern medicine"

-Dr. Josef Wang

"Pain is more terrible lord of mankind than even death himself"

Albert Schweitzer

"Perfect misery is pain, the worst of all miseries; and in excess, overcomes all patience"

-Milton:

Paradise Lost

"Pleasure is oft a visitant; but pain clings cruelly to us"

-John Keats

"Pain is the inseparable companion of any operation"

-Velpau, 1837

"Pain can kill"

-John Liebeskind, Ph.D. UCLA

Former President,

American Pain Society

"Prolonged pain destroys the quality of life. It can erode the will to live"

-Ronald Melzack, Ph.D.

McGill University

"Pain can be controlled by reason"

-Descartes

-Spinoza

"Pain is not a passive symptom. It is an aggressive symptom in the central nervous system"

-Ronald Dubner, DDS, Ph.D.

National Institutes of

Health

"Pain is nature's cry in distress and a call for help in danger. This is true both of the physical and the moral organism"

-R.V. Ihering

"It is impossible to draw a clear distinction between itch and protopathic pain"

-Rothman

"Pain has never been defined satisfactorily"

-Federick Prescott

The Control of Pain

It should be obvious to everyone that the topic of pain, acute or chronic, is a very complicated one.

Its interpretation by the victim who suffers it, as a symptom or as a disease, is subject to his or her motional state and/or physiological state.

Both, the Physician and the Patient who suffers pain, should be always aware of the variations in the sensation of pain so well illustrated by the expressions and thoughts of the prominent writers, both lay and scientists, that we have quoted.

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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

III Congreso Nicaragüense de Anestesiología aracnoidits y aspectos médico legales en anestesia. "Radiología de la columna vertebral para anestesiólogos." "Etiología y patofisiología de la arachnoiditis." "Prevención de la arachnoiditis por anestesia neuroaxial." "Arachnoiditis por intervenciones quirúrgicas y procedimientos intervencionistas." "Un mundo sin oxido nitros." "Modificaciones a la escala de Aldrete." Managua, Nicaragua, March 27-29, 2003.

Simposiom Internacional del dolor Puebla 2003. "Síndrome de la espalda fallida. ¿Quién falló?" Puebla, Mexico, May 8, 2003.

VIII Congreso Dominicano de Anestesiología. "Círculo casi Cerrado," "Un mundo sin Oxido Nitroso." Santo Domingo, Dominican Republic, June 12, 2003.

VIII Congreso Dominicano de Anestesiología. "Modificación de la Escala de Aldrete," "Radiología de la columna verebral lumbar," "Etiología y patofisiología de la Arachnoiditis,"

“Aracnoiditis causada por Anestesia neuroaxial.” Santo Domingo, Dominican Republic, June 13, 2003.

Asociacion Argentina de Anestesiólogos Buenos Aires. “The cascade of oxygen in the pulmonary system,” “Allergy to local anesthetics.” Buenos Aires, Argentina, July 16-18, 2003.

Asociacion de Anestesiólogos de Cordoba. “Modificaciones al esquema de Aldrete,” “Causas y Fisiopatología de Aracnoiditis,” “Anesthesia Regional y Aracnoiditis.” Cordoba, Argentina, July 19, 2003.

“Modificaciones al Esquema de Aldrete.” Hospital “Garragan,” Buenos Aires, Argentina, August 22, 2003.

“Aracnoiditis por anestesia neuroaxial.” Hospital “Ramos Mejia,” Buenos Aires, Argentina, August 24, 2003.

2º Curso de Actualización en Anestesiología. Colegio de Anestesiólogos del Estado de México A.C. “Circuito Casi Cerrado,” “Modificación a la Escala de Aldrete.” Hotel Del Rey Aeropuerto, Toluca, México, August 6, 2003.

IX Curso de Anestesia en Ginecoobstetricia de Alto Riesgo. “Aracnoiditis, la Epidemia Silenciosa”, “Anatomía Aplicada en bloqueos Regionales Espinales”. Hotel Real de Jon Juan, Tepic, Nayarit, México, September 13-15, 2003.

American Society of Anesthesiologists 2003 Annual Meeting, San Francisco, California:

“Who presents free papers at the annual Meeting of the American Society of Anesthesiologists?” Propanolol and Acetazolamide in patients with postlaminectomy pseudomeningocele.” Comparison of epidural Indomethacin to Methylprednisolone in Diabetic Patients.” Nerve root axon regeneration after intrathecal injection of phenol.”

“Causes of Aracnoiditis.” October 11-15, 2003.

“Early History of Anesthesia for Liver Transplantation.” Grand Rounds, Anesthesiology UAB. University of Alabama in Birmingham, October 20, 2003.

“Síndrome de cirugía fallida de espalda.” Academia Mexicana de Cirugía, México D.F., México, October 21, 2003.

“Cervicobraquialgias”, “Indometacina por Vía Peridural, una alternativa a los esteroides.” VII Congreso Internacional de Clínica del dolor y cuidados paliativos (amal). Tampico, México, October 23-26, 2003.

“Aracnoiditis, causas, diagnóstico y tratamiento”, Invitado por el Ministerio de Salud Pública de Cuba y La Sociedad Cubana de Anestesiología y Reanimación, La Habana, Cuba, November 5, 2003

“Cervicobraquialgias”, “Anatomía radiológica de la columna vertebral para anestesiólogos”, “Actualización del score de Aldrete” Invitado por el Ministerio de Salud Pública de Cuba y La Sociedad Cubana de Anestesiología y Reanimación, La Habana, Cuba, November 6, 2003.

“Presentación del libro “Anestesiología Teórica Práctica.” XXXVII Congreso Mexicano de Anestesiología y Curso de Actualización, Zacatecas, Mexico, November 19-22, 2003.

PUBLISHED MANUSCRIPTS, ABSTRACTS AND CHAPTERS IN 2003

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Aldrete JA: Epidural Injections of Indomethacin for Postlaminectomy syndrome: A preliminary Report. *Anesth Analg* 96:463-8, 2003.

Aldrete JA: La Investigación Clínica en Latinoamérica. *Rev Clinica Dolor y Terapia* 2003;1:10:15-16.

Ríos JJ, **Aldrete JA:** Justificación de la denominación de nuestra especialidad: algología. *Rev Soc Esp Dolor* 10:2:116-118, 2003.

Aldrete JA: Letter to the Editor. Recurrent neurological symptoms in a patient after repeat combined spinal and epidural anaesthesia. *Br J of Anaesth* 90:3:March 2003.

Aldrete JA: Dr. Aldrete Comments On the Findings By Ahmad et al. *Anesthesiology News* Page 42-3, April 2003.

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Aldrete JA: Causes of Arachnoiditis. ASA annual Meeting, pp 347, October 2003.

Aldrete JA: Comparison of epidural Indomethacin to Methylprednisolone in diabetic patients. ASA annual Meeting, pp 306, October 2003.

Aldrete JA: Propranolol and Acetazolamide in patients with postlaminectomy pseudomeningocele. ASA annual Meeting, pp 306, October 2003.

Aldrete JA: Who presents free papers at the annual meeting of the American Society of Anesthesiologists? ASA annual Meeting, pp 260, October 2003.

Aldrete JA: Nerve root axon regeneration after intrathecal injection of phenol. ASA annual Meeting, pp 280, October 2003.

Aldrete JA, Ginesta V: Antecedentes históricos de la anestesia. In: *Texto de Anestesiología Teórico-Práctica. 2ª edición.* Manual Moderno – Mexico City, Mexico, 2003, pp 3-28.

Espinal Gallegos M, **Aldrete JA:** Fisiología cardiovascular. In: *Texto de Anestesiología Teórico-Práctica. 2ª edición.* Manual Moderno – Mexico City, Mexico, 2003, pp 117-40.

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Aldrete JA: Conservación de la sangre. In: *Texto de Anestesiología Teórico-Práctica. 2ª edición.* Manual Moderno – Mexico City, Mexico, 2003, pp 725-31.

Aldrete JA: Laparoscopia, toracoscopia y nefroscopia. In: *Texto de Anestesiología Teórico-Práctica. 2ª edición.* Manual Moderno – Mexico City, Mexico, 2003, pp 1033-47.

Aldrete JA: En las Alturas. In: *Texto de Anestesiología Teórico-Práctica. 2ª edición.* Manual Moderno – Mexico City, Mexico, 2003, pp 1255-63.

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Mesa AM, **Aldrete JA:** Trasplante de órganos. In: *Texto de Anestesiología Teórico-Práctica. 2ª edición.* Manual Moderno – Mexico City, Mexico, 2003, pp 1427-46.

Aldrete JA: Bioterrorismo. In: *Texto de Anestesiología Teórico-Práctica. 2ª edición.* Manual Moderno – Mexico City, Mexico, 2003, pp 1499-1510.

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Texto de Anestesiología Teórico-Práctica. 2ª edición. Aldrete JA and Associate Editors. Manual Moderno – Mexico City, Mexico, 2003.

Cefalea, migraña y algias cefalocervicales. Aldrete JA. Editorial Alfil – Mexico City, Mexico, 2003.

CALL FOR DONATIONS TO THE ARACHNOIDITIS FOUNDATION TO CONTINUE TO FUND THE RESEARCH THAT HAS BEGAN.

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 dollars 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 taldrete@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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YOUR DONATION WILL HELP TO LEARN MORE ABOUT ARACHNOIDITIS