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FROM THE EDITOR'S DESK

An incredible increase of web sites dealing with ARACHNOIDITIS has been noted; this is not surprising as those that feel that have something to say ought to go and say it, specially some of the patients experiencing this terrible disease who want to share their pain, despair, disappointments and somber future with others and those than want to offer some kind of services or cures, after all it is a free country and any one can say what they want in the internet.

It is however different if some unqualified and mal-intentioned individual that ingeniously manages to set a web site to derive some kind of gain whether monetary, positional or organizational. PATIENTS, PLEASE beware of pseudo experts that want to create groups that require subscriptions, fees, contributions, etc. For whatever reasons, it seems that patients seeking advice may be misled into one of these groups only to find out that the promises and flashy web site are great enticers but lack substance and veracity, consisting mostly of regurgitated material published by some one else, statements should be constructive rather than demeaning, deceiving or misleading. .

Following our commentaries in the last two Newsletters, the FDA appears to have undergone some organizational changes following the embarrassing approval and disapproval of VIOXX which has been followed by the removal of CELEBREX from the market and the possibility that other similar Coxx2 inhibitor drugs may follow the same fate. Among the discouraging facts that have emerged has been the harassment of their own FDA expert, Dr. David J. Graham who issued the first warning about VIOXX but was forced to issue a wishy-washy report rather than the truth; since then, he has told Congress' investigators that he was "ostracized" and subjected to "veil threats" and intimidation by senior members of the Agency after his insistences that Vioxx was potentially dangerous to some patients in the dosages used un the study of colon cancer prevention. Since then, Dr. Graham has also described to the Congressional investigators that raising safety concerns within the inner group of the FDA was extremely difficult and that the approach followed at the present, the so

called “scientific peer reviews” exposed those that raise questions and disagree with the silent majority to criticism by the senior leadership of the agency and endanger their jobs.

Without any of these two medications some patients have found without appropriate treatment; what can they do? There is another “one pill a day” medication Bacitra that seems to have similar favorable effect on illnesses characterized by chronic inflammation.

Also alarming has been the revelation that intra-agency pressure was applied on Dr. Andrew Mosholder, another FDA epidemiologist that first called attention to the apparent non-coincidence that children taking some antidepressants were more prone to commit suicide. He was told to “soften” his recommendations. By the way the least risky of the antidepressant drugs studied was found to be Prozac.

If one looks at the studies with VIOXX, the dosage used in the anticancer study was twice as much as the dosage to treat arthritis; apparently the manufactures figured that if 100mg was good, 200mg should be better. But it did not work that way that is how they got into trouble. It seems that all corporate transgressions occurring in the last decade or so began soon after Mr. Gecko, the character portrayed by Michael Douglas as a CEO of a power house in the movie “Wall Street”, in his speech to the investors made the resounding remark ‘GREED IS GOOD”. From there on, all the Kowzlokis, Scrushis, Stewarts, and other senior leaders felt that their abbreviated title CEO stood for “cheeter executive officer” so hiding the real economical situation of their corporation and misleading their investors were justified, as long as they themselves derived some huge) personal gain.

These and similar corporate crooks seem to follow Gecko’s aphorism. In other words, to ”walk the line’ is alright and to step over the line is even better, if you get away with it.

Now, we have to face the reality that we can not trust the FDA as a regulatory agency and guardian of drug quality. The latest fiasco includes the so called botulism toxin labeled as “Botox”; at least two cases of injection of this substance for cosmetic procedures have resulted in severe intoxication. One couple from Palm Beach Gardens, FL received about 2 ml of the medication that turned out to be a raw, potent unapproved form of botulinum toxin to smooth some wrinkles in the face. Within days, they began to loose strength and when the diagnosis was finally made, they were flown to the Center for Infectious and Communicative Diseases in Atlanta; by then they were bedridden and ventilator dependant. Nine months later they had difficulty walking, they were pale, weak and one of them still needs to use a cane to be able to get around. Evidently, an osteopath administered the preparation to this couple, to his girl friend and to himself. The latter couple was treated in New Jersey. This physician obtained the preparation from an outfit called List Biological Laboratories in California, sold through the internet. (South Florida Sun-Sentinel, Feb. 5, 2005, pages 1 and 5). This latest incident may serve as a warning to those that

purchase medications sold in the internet. However, from what we have been discussing before, it is obvious that we can not trust even the medications approved by the FDA and sold in regular pharmacies. What advice can I give you, only take whatever medication that you need and only have surgical or invasive procedures that are life or organ saving; the rest remains a gamble.

Every effort to have the Federal Government to allow individual citizens to import medications from other countries, has been derailed by the US drug manufacturers; the latest objection was that the FDA can not guarantee the quality of medications purchased abroad. As if it does, on the drugs that it approves. We do not believe on its safety record. It seems that the solution of the crisis with sulfadiazine in the 30's and the prevention of sales of thalidomide in the 60's successes, the Agency has lived on the reputation obtained in those two instances, but in reality it has been downhill as many of us have felt that they have become too close and in some cases, dependant of the same industry that they suppose to regulate.

The Agency's opposition to the purchase of medications from other countries has revealed a paradox since most of the drugs that would be purchased are manufactured by Abbott, Aventis, Pfizer, Merck, Pharmacia, Astra and other companies with their main offices in the USA. If the FDA does not trust their products manufactured in Canada and Mexico, how come we do not warn Canadians and Mexicans that the medications that they currently receive are lousy drugs. The fact is that the drugs are exactly the same, they have the same ingredients and their manufacturers apply the same quality control in their plants as in the USA. Simply, that argument "does not hold water", is fictitious and a plain non-truth. The FDA can not have it both ways, they do not allow patients to bring less expensive medications manufactured in Mexico and Canada by the same laboratories that manufacture them in the USA! I just do not understand it.

INQUIRIES

I need to state that to protect patient's confidentiality under HIPAA, I do not offer medical opinions over the Internet. However, not uncommonly, our web site receives inquiries about certain issues and if they are related to arachnoiditis.

MEMORY

Some patients with arachnoiditis have confided in me, that since they developed ARC, their memory is not the same. It is easy to attribute this memory loss to some of the medications they take; however this loss may be more complex than we would like to think. It is now known that head injuries may result in temporary or permanent amnesia

There are numerous movies and books about partial, selective and expanded memory loss resulting from head injuries, traumatic psychological events and certainly from the repeated ingestion of certain type of medications such as the diazepine group (Valium, Xanax and others). The current understanding is that when we are

introduced to a an unknown person, we store the persons name in the “short term” memory but it may be gone in a few minutes; however, some important information like the name of your best friend is stored in the “long term memory” compartment and may persist there for a life time. Not until recently, has this mechanism for classifying what goes into one or the other has been clarified and located somewhere in a portion of the brain called the hypocampus with intricate connections to the cortex and the mecencephalus. At any rate taking certain types of medications such as those mention, opiates some antidepressants , tranquilizers, sedatives for a long term, may affect both the short and the long term memories, as well as, repeated worries, fears and distractions.

A debate has been going on for centuries trying to define whether the aging process produces loss of memory; certainly micro emboli or infarcts of vessels in certain areas of the brain (mini-strokes) may reduce the capability of storing certain events, names etc in the memory, but in addition, other have equated the memory to a bucket with a spout at certain level; as we live a long live of events, names, locations, experiences, the ”bucket” gets filled and eventually, the excess of memories saturates the buckets, with the most recent getting “spilled” out of the bucket through the spout. To some, this may represent a very simplistic explanation, but on the other hand it does help to understand why we can remember events and persons we met half a century ago but not some casual acquaintance that we were introduced to, last month.

As a matter of clarification though, it must be emphasized that in the elderly, if there is lack of recognition of close relatives, addresses, telephones and recent events patients should be examined by their physician, and refer to a neurologist to rule out, dementia, Alzheimer’s disease and any other condition resulting in consisting and permanent memory loss.

Otherwise, we must “exercise” our memory as we exercise our bodies, for example try to remember the seven or ten digits telephone numbers when you are calling unfamiliar numbers; when you are writing checks read the account numbers of your bills and try to remember them as you write the checks; add, subtract, multiply and or divide by hand instead of using calculators. Cross word puzzles are also quite useful. The substitution of some of the medications known to affect memory need to be discussed openly and frankly with each patient’s physician.

UNDERSTANDING THE CAUDA EQUINA SYNDROME

This neurological entity has been known for more than a century, nevertheless, until recently has been recognized as a clinical syndrome with few cases of objective and precise definition as to what cause it and where specifically is the lesion. Of late, the mechanisms involved in this neurological deficit have been unveiled identifying at least three causes for its occurrence:

- Ischemic, usually resulting from a temporary or permanent occlusion of the circulation to this, the most distant portion of the spinal cord; specifically the one single vessel called the Adamkiewicz artery may be occluded during certain pelvic or spinal operations and specially in operations of the abdominal aorta. Placing patients in compromising positions (legs up, on their side, overstretched and then placing heavy retractors can reduce or occlude the blood flow). Since the cauda equina receives about half of its nutrients from its blood supply, the rest is taken from the cerebrospinal fluid; therefore, any reduction of blood flow may affect the delivery of vital oxygen. Occlusion of the blood supply may also be caused by atherosclerosis.
- Chemical injury resulting from toxic substances injected into the subarachnoid space, such as the administration of high dosages or concentration of local anesthetics (5% lidocaine or more than 14mg of bupivacaine) for spinal anesthesia. Some were too toxic to be tolerated such as effocaine, chirocaine, 3% choloroprocaine and others well known neurotoxic substances somehow are still being injected "incidentally" into one of the most delicate spaces of the human body; they include hypertonic (10%) saline, polyethylene glycol, phenol, 100% alcohol and methylene blue that for no valid reason, some how end up surrounding the spinal cord and the spinal nerve roots. Depending on the site of injection and of each substance specific gravity, these chemicals may injure the cauda equina at the L_1 and L_2 levels or by gravity they end up in the most dependant portion of the dural sac, injuring the sacral nerve roots.
- One more mechanism is the direct injury of the medial portion of the thoracic spinal cord where the sacral descending fibers are located, this may include repeated attempts to thoracic epidural anesthesia or trauma from the introduction of catheters, electrodes (from spinal cord stimulators) or certain surgical procedures whether from accidental cutting, cautherization of a small nerve rootlet or by simply maintaining to much pressure or for too long periods on the nerve roots by surgical retractors.

From the latter, at least three types of lesions can occur at any of these points that may result in the loss of bladder or bowel control and loss of sensory feeling around the pelvic, perineum ("bottom") areas, as well as certain degree of sexual dysfunction.

1. ***NEUROPRAXIA*** *is the temporary loss of function (conduction) of any nerve root or nerve trunk resulting in loss of function (paralysis and or numbness) without structural changes or Wallerian degeneration; lasting more or less from 3 to 12 days. A typical example is dribbling or incontinence for a few days.*
2. ***AXONOTNESIS*** *in which damage to the axons of a nerve or nerve root occurs without damage to the support structures (perineurium, Schwan sheet or the myelin cover). The axons may or may not recover and if they do, usually do not maintain the normal density or distribution, which clinically results on some restoration of function, but seldom to full normality. An example is a "drop foot" that partially recovers*

3. ***NEUROTNESIS*** *is defined as the complete anatomical section of the nerve or nerve root (including axons and structural supports) with permanent Wallerian degeneration of the distal section of the nerve or nerve root resulting in complete sensory and motor loss. In which there is permanent loss of bladder and or bowel function or a permanent "drop foot).*

At any rate all of these lesions are matter of concern but the latter two are certainly devastating. Patients contemplating spinal intervention, anesthesia, injections, or surgical procedures in or around the spine, ought to discuss the odds for complications, such as those mentioned above, to happen.

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 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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