

Aldrete recently noted in his online Newsletter (December 2002), that research is being carried out in Mexico City by doctors who have already been investigating spinal cord injuries.

Rat studies have been used to develop an experimental model of arachnoiditis. Dr. Aldrete notes that this will be vital in permitting the comparison of effects from chemicals such as saline, polyethylene glycol etc. with those produced by phenol.

He also remarked that surgery alone can cause meningeal damage, nerve root clumping and axon demyelination.

Aldrete comments in his book, "Arachnoiditis -The Silent Epidemic":

"The tremendous impact that this disease has among middle-aged, productive people is enormous....with most of them disabled, divorced, depressed, angry, involved in litigation,"

and in his commentary at the end of the chapter, concludes that:

"Since the most common cause of lumbar ARC is usually an iatrogenic event resulting from a complication of a diagnostic or therapeutic procedure, the medical community must therefore take an introspective look at itself without skepticism and reluctance.

There is little doubt that today, interventional procedures of the spine are the etiology in most of these cases."

Dr. Bourne, whose wife suffered from arachnoiditis, wrote: ([1](#)):

“The relentless and progressive pain syndrome of arachnoiditis is taxing to the patient's morale. In many instances doctors, relatives and friends fail to realise that the pain can be as bad as terminal cancer, without the prospect of death to end the suffering. Well-meaning enquiries as to whether there is any improvement with the implication that there must inevitably be improvement...are distressing to the patient.

There are sympathetic doctors, relatives and friends who expect the patient to be brave, stoical and cheerful. In the end the patient yearns for less exhortation and more compassion. Compassion is an important consequence of comprehension of the existence and nature of arachnoiditis.”

We must keep in mind that, far from being a medical anachronism, adhesive arachnoiditis continues to present an ongoing challenge to the medical community and remains a source of terrible suffering throughout the world.

The profile of this condition needs to be raised in order to initiate vital research into possible avenues of treatment and better still, prevention.

The 2001 New Zealand report's closing recommendation serves as a timely reminder:
“Prevention will be an important aspect of health strategies to address this condition given the recognised etiology...particularly the prevention of post-operative and post-injection complications.”

Numerous support groups around the world strive against great odds (often run by sufferers) to bring the story of arachnoiditis into both the medical and public arenas.

Many individuals struggle day to day to maintain hope in the face of an incurable and devastating condition. They remain faceless and nameless, but their courage should not be forgotten.

The NZHTA report, whilst commending the involvement of various support groups, citing them as a useful resource and

"an important impetus to future research";

acknowledged that "it is not clear how co-ordinated and systematic research into arachnoiditis will proceed."

Nevertheless, we must continue to work steadily and determinedly towards what may thus far seem an invisible and maybe impossible goal.

In summary, we need a 3-pronged attack on arachnoiditis:

1. Recognition of cases, leading to statistics on prevalence.

2. Proactive approach to treatment

3. Prevention of further preventable cases.

In order to achieve these aims we need:

Education and Research

As Dr. Charles Burton wrote in 1999,

“The subject of adhesive arachnoiditis is still something no one really seems to hear anything about. They will, I assure you, continue to hear about it because it is still a clear and present health affliction and we will do our best to continue to make the public aware of this condition and hopefully, to bring some recognition and respect to sufferers.”

I hope this article will help raise awareness, provide education and promote research. Most of all, I hope that it gives sufferers hope for the future, whilst aiding them in the midst of their present afflictions.

Dr Sarah Smith (Andreae-Jones) MB BS, Patron of ASG (UK), ASAMS, New Zealand, COFWA, USA and CIAASA, Australia.
October 2003

[1] Bourne IHJ *Journal of the Royal Society of Medicine* 1990 April 83 Lumbo-Sacral adhesive arachnoiditis. A review.