Australian Arachnoiditis
Sufferers Queensland
Association Inc.

Registration No: 1A 32655
President: Peter J. Groves

PARLIAMENTRY INQUIRY
INTO
CHRONIC DISEASES
IN THE
QUEENSLAND COMMUNITY

"ARACHNOIDITIS"

A TOXIC CHEMICAL

TRAGEDY

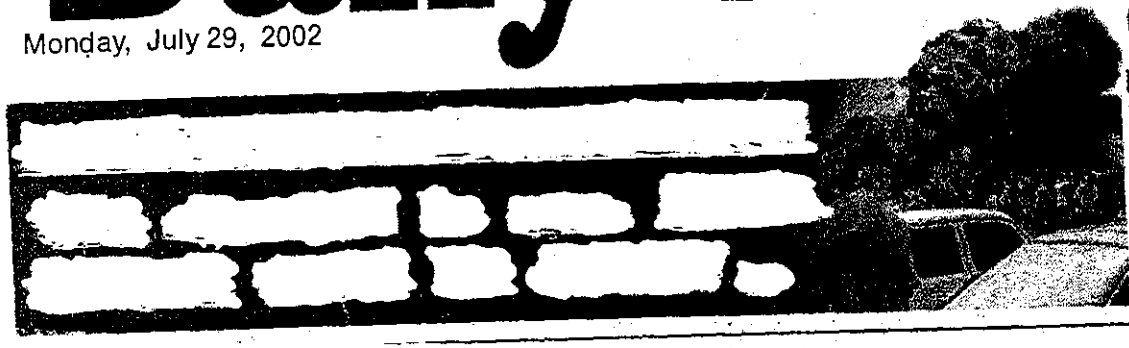
2009

Postal address: The Secretary - P.O. Box 1118 - Palm Beach, Gold Coast Queensland 4221 - Australia
Phone: (07) 5535 6655 Fax: (07) 5535 6655
Email: peter.groves@aasqa.org Website: www.aasqa.org info@aasqa.org

THE
Daily Telegraph

Monday, July 29, 2002

$1*
Including GST XM



Exclusive: 42-year medical cover-up exposed

SPINE CHILLING

By SUE DUNLEVY

THOUSANDS of Australians are living in chronic pain after their spines were injected with a dye in an X-ray procedure that was used for 42 years.

The Daily Telegraph has documentary proof the Federal Government, state health authorities and doctors sanctioned the use of the dye even though they knew the devastating effects of the chemicals in it.

The dye enabled doctors to see the spine more clearly in a type of X-ray called a myelogram and was used between 1945 and 1987.

Victims of the dye's effects suffer burning back pain, incontinence, loss of bladder control, visual impairment, seizures and paralysis.

Known as adhesive arachnoiditis, the disease is caused by the inflammation and fusion of the nerves and membranes of the spinal cord.

The condition can take up to 10 years to develop.

Derek Morrison, a sufferer who has spent 10 years researching the dye's use and has organised a national support group for around 3000 Australian sufferers, is demanding an independent inquiry into the use of the chemical.

Mr Morrison can't believe the government licensed the chemical for use.

"You've seen the chemical make-up of the substance — it contains benzene, hydrochloric acid and sulphuric acid," he said.

"How could they ever think that

Continued Page 2

Miners rescued after three days below ground — P21

Cloudy with isolated showers developing later. Cool: P54

AUSTRALIAN
ARACHNOIDITIS
SUFFERERS
QUEENSLAND
ASSOCIATION Inc.®
Registration No: 1A 32655

President: Peter J Groves
Ph: (07) 55356655
Mail: The Secretary
P.O. Box 1118
Palm Beach
Gold Coast
Queensland 4221

AASQA SUBMISSION AGENDA FOR

PARLIAMENTRY INQUIRY INTO CHRONIC DISEASES IN THE

QUEENSLAND COMMUNITY 2009

SYDNEY DAILY TELEGRAPH EXPOSE`2002

- 42- year medical cover-up exposed **"SPINE CHILLING"**
- Definition of Arachnoiditis, posted on gateway to neurology at Massachusetts General Hospital.
- Three distinct stages of Myodil Adhesive Arachnoiditis
- Arachnoiditis brochure produced by Flinders University 'Disability and Community Rehabilitation' researcher Neil Fitton.
- Arachnoiditis , A Toxic Chemical Tragedy. Article written by Gil May in Nexus Magazine August 2006.
- Historic High Court judgement for AASQA President Peter J Groves in the right for damages compensation from the Government, for ex-servicemen and women for negligence.
- Gold Coast Mail story March 7,2008 'ONE MAN`S FIGHT FOR JUSTICE`.
- 1,2,3,4 entries from Daily Telegraph expose` July , August, 2002.
- "Call for Inquiry into Lethal Procedure", story in Gold Coast Sun Wednesday , June 22, 2005.
- " Peter`s medical mission", story Gold Coast Mail October 2, 2002
- Griffith University School of Medicine Certificate of Appreciation, For participation in the `Health in the Community Component of the Medical Program 2007.
- Introduction to Adhesive Arachnoiditis by Dr Sara Smith (nee Andreae-Jones)MB BS. Also a sufferer of Arachnoiditis.
- AASQA Submission 6785 `A LONG TERM HEALTH STRATEGY`, Australian 20/20 Summit
- AASQA May newsletter 2008.
- Reproduction paper which introduces: Formula for ***`Iophendylate(Pantopaque/Myodi)`,*** to the medical establishment at Oxford University at the height of world war 2, 1944.

- Paper to referring to **`FLARE UPS`,Every arachnoiditis sufferer will have experience a `Flare up`, at some time or other.**
- Arachnoiditis Poster with 80 related medical conditions listed by the American FDA 1998, as the cause and effect of Iophendylate (Pantopaque/Myodil).
- Subission to National Health Strategy, held at the Gold Coast 20/20 summit April 2008.
- Arachnoiditis –" The Silent Epidemic", a newly published book by J Antonio commentary on page 215, chapter on clinical diagnosis.The book describes the concepts expressed in his website in depth with supportive medical bibliography.
- An addendum to " How the Dye was Caste",A paediatric text book from 2003 from Papua New Guinea detailing use of Myodil in Babies, using 3,6 or 9 mls and not aspirating.
- Enclosed is the CD **"Australia`s Greatest Shame", MYODIL.**
- Business card for AASQA President Peter J Groves

REGARDS,

Peter J Groves

President (AASQA)

Australian Arachnoiditis Sufferers Queensland Association Inc

P.O. Box 1118

Palm Beach Qld 4221

Ph 0755356655

Mob 0428 356655.

AUSTRALIAN
ARACHNOIDITIS
SUFFERERS
QUEENSLAND
ASSOCIATION Inc.®
Registration No: 1A 32655

President: Peter J Groves
Ph: (07) 55356655
Email: petergroves@aasqa.info
Mail: The Secretary
P.O. Box 1118
Palm Beach
Gold Coast
Queensland 4221

ARACHNOIDITIS

ARACHNOIDITIS IS A CONDITION, WHICH BEGINS WITH INFLAMATION OF THE ARACHNOID MEMBRANE COVERING THE SPINAL CORD AND BRAIN.THIS CAN CAUSE A GRADUAL BUILD UP OF FIBROTIC SCAR TISSUE, WHICH TETHERS THE NERVES TO THE ARACHNOID MEMBRANE. THIS SCARRING DISRUPTS THE FLOW OF CEREBRO SPINAL FLUID(CSF)AROUND THE NERVES AND DEPRIVES THEM OF NUTRITION.

THE EARLY SYMPTOMS OF THIS CONDITION CAN BE ALL OR SOME OF THE FOLLOWING : SEVERE LOW BACK AND LEG PAIN, NUMBNESS AND CHRONIC PAIN IN LEG(S)AND/OR FEET, BURNING SENSATIONS ESPECIALLY IN THE LEGS AND FEET,BLADDER AND BOWEL DISFUNCTION,AND SEVERE HEADACHES.MANY PATIENTS WITH THIS CONDITION COMPLAIN OF FEELING OF WALKING ON BROKEN GLASS.OFTEN THERE ARE NO OUTWARD SIGNS OF THE CONDITION AND SUFFERERS LOOK DECEPTIVELY "NORMAL".AS THE CONDITION PROGRESSES THE SYMPTOMS MAY INCREASE AND BECOME MORE PERMANENT. SOME PATIENTS USE WHEEL CHAIRS ,AND MOST PATIENTS WITH ARACHNOIDITIS HAVE TO GIVE UP WORK ENTIRELY.

KNOWN CAUSES OF THE CONDITION ARE THE FOLLOWING TUBERCULOSIS, MENINGITIS, SPINAL TUMORS ABCESSES, SPINAL SURGERY OR TRAUMA. BY FAR, THE LARGEST SINGLE CAUSE IS MEDICAL INTERVENTION SUCH AS MYELOGRAMS , RADICULARGRAMS, EPIDURALS ,(STEROIDS) AND LUMBAR PUNCTURES. (THIS DEFINITION WAS POSTED ON GATEWAY TO NEUROLOGY AT MASSACHUSETTS GENERAL HOSPITAL)

WEBSITES;
WWW.BURTONREPORT.COM

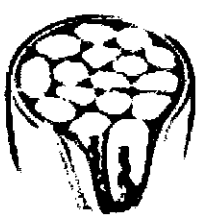
WWW.ABOUTARACHNOIDITIS.ORG
WWW.THEAWORD.ORG

Chemically Induced Adhesive Arachnoiditis Sufferers Of Australia®

THREE DISTINCT STAGES OF MYODIL ADHESIVE ARACHNOIDITIS.

1.

The first stage of Myodil Adhesive Arachnoiditis



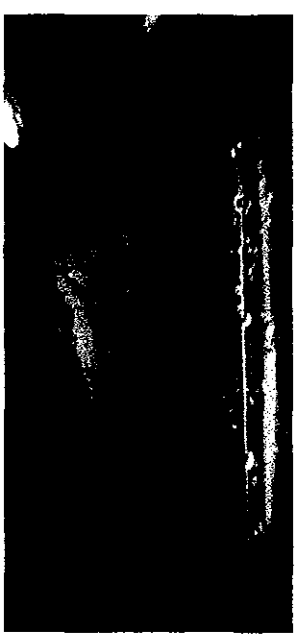
30/09/2002

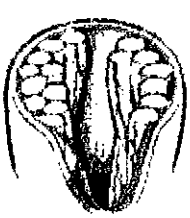
Normal View of Subarachnoid Space

Nerves roots markedly swollen

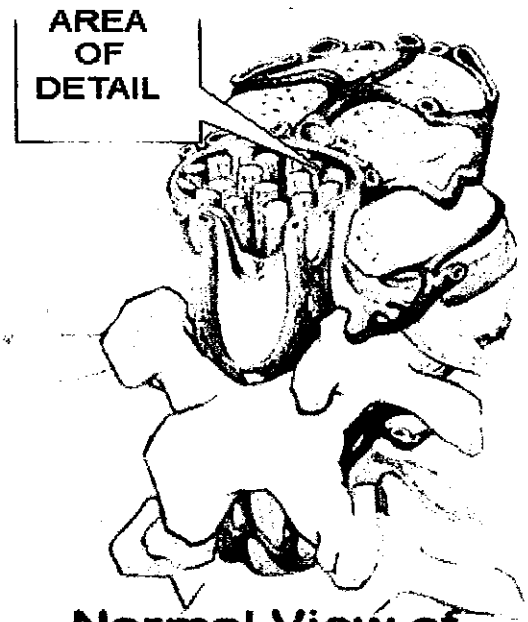
The second stage of Adhesive Arachnoiditis

2.





30/09/2002



Normal View of Subarachnoid Space

Atrophy of nerve roots with scar proliferation. Residual Myodil present in spinal fluid

The third stage of Adhesive Arachnoiditis

3.

30/09/2002

SUPPORT & MANAGEMENT

Methods of treatment

- Pain management with narcotics [2]
- Steroids [2]
- Spinal cord stimulation [2]
- Surgical removal of scar tissue (sever cases) [2]
- Physiotherapy [4]
- Exercise [4]
- Psychotherapy [4]

Support Groups

- Australian Arachnoiditis Sufferers Queensland Association (AASQA) http://www.aasqa.org.au
- Australian Arachnoiditis Sufferers Association NSW http://www.aasansw.org.au

REFERENCES

[1] Deshmukh, V, 2003, 'Arachnoiditis', Encyclopedia of Neurological Sciences, p. 255-256, Elsevier Science Ltd

[2] Wright M, 2003, 'A comprehensive Review of Spinal Arachnoiditis', Orthopedic nursing, Vol. 22, Iss. 3, p. 215-219, Lippincott Williams and Wilkins, Hagerstown MD

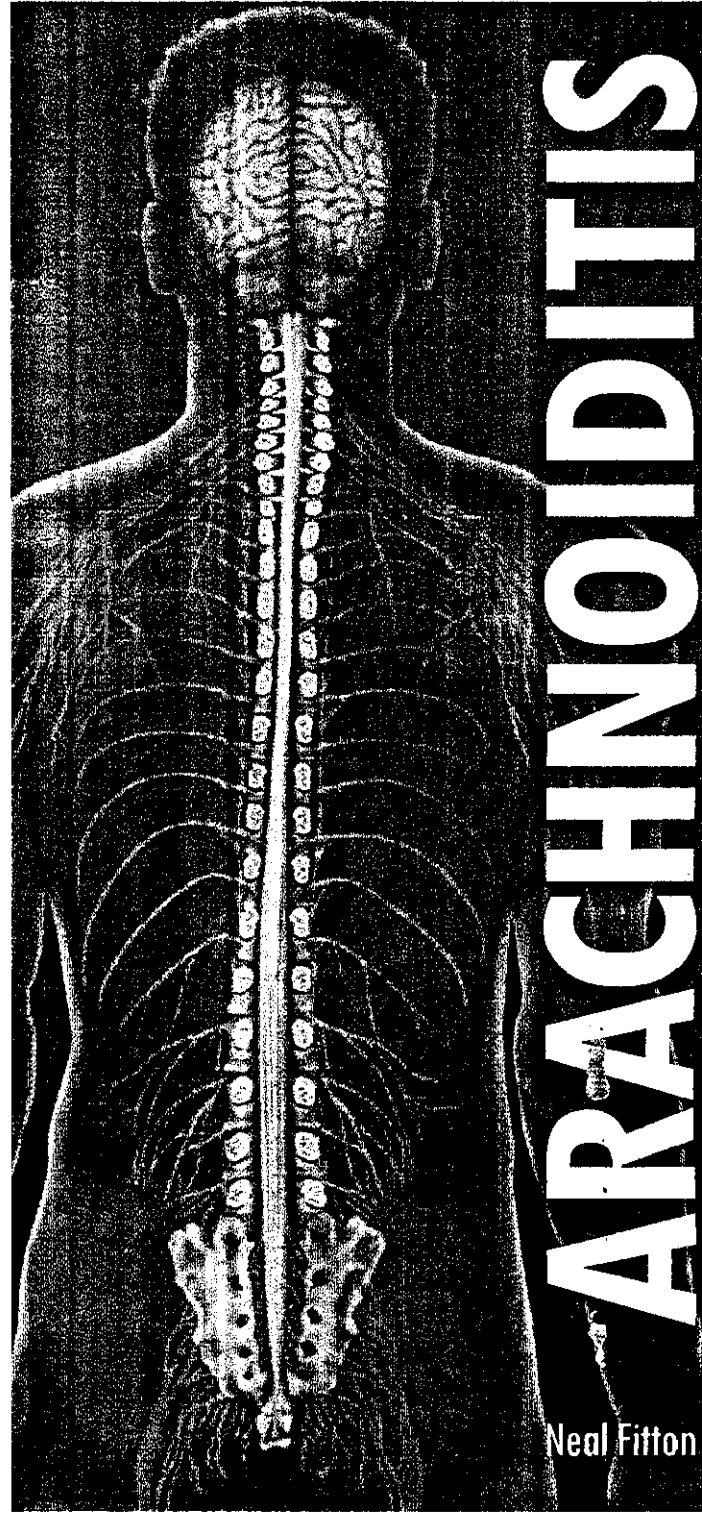
[3] Gray, H, 1977,' Gray's Anatomy, The Classic Collector Edition, Bounty Books, New York

[4] National Institute of Neurological Disorders and Strokes (NINDS), 2007, Disorders, Arachnoiditis, Communications and Public Liaison, Bethesda MD, http://www.ninds.nih.gov/disorders/arachnoiditis/arachnoiditis.htm

[5] Davidson, 2006, 'Presenting problems in musculskeletal disease', Davidson Principles and Practice of Medicine, p 1085, Elsevier Ltd, India

[6] Neurological Council of SA Inc, 2008 , 'Supporting people with Physical and Neurological Disorders', Spina Bifida and Hydrocephalus Association SA

[7] Eldon, T, 2008, 'Epidemiology of Chronic Pain With Psychological Comorbidity: Prevalence, Risk, Course, and Prognosis', Canadian Journal of Psychiatry, Vol. 53, Iss. 4, p. 224-235



ARACHNOIDITIS

Neal Fitton

WHAT IS ARACHNOIDITIS?

Arachnoiditis

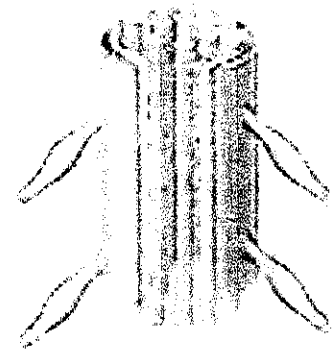
The term arachnoid is derived from the Greek word archne (spider) and cides (shape) (1). The arachnoid is one of three membranes that surround the brain and spinal cord [2]. The arachnoid membrane is extremely thin and delicate and is referred to as a spider's web [3]. The brain and spinal cord are surrounded by three membranes [2]. The dura and pia membranes encompass the arachnoid membrane [2]. These membranes cover, protect and provide cushioning to the spinal cord and spinal cord roots [2]. Arachnoiditis is an inflammation of the arachnoid membrane [4].

Causes

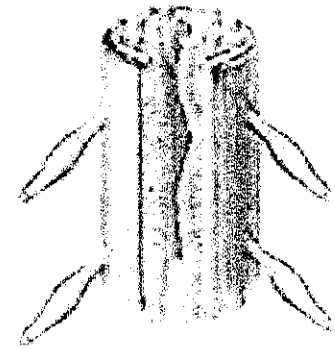
Arachnoiditis is caused by infections, trauma, spinal cord contamination, spinal cord tumors, and genetics [2]. Spinal cord contamination results from injecting foreign substances, such as steroids, contrast media, or antibiotics into an individual's body via the spinal cord [2]. The arachnoid membrane may not immediately become inflamed after the procedure [2]. It may take years for arachnoiditis to become evident [2].

The Progression of Arachnoiditis

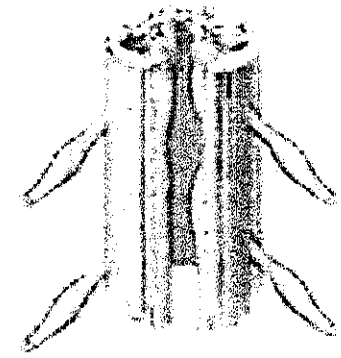
A. The arachnoid layer and spinal nerves are inflamed and irritated [2].



B. Increased scarring of the arachnoid results in the spinal nerves sticking to the arachnoid [2].



C. Hardening of the scar tissue binds the spinal nerves to the arachnoid [2].



Main Characteristics

- Burning pain in the lower back and legs [2]
- Loss of sensation [4]
- Skin rashes and itching [2]
- Muscle cramps, twitches or spasms [4]
- Burning in the ankles and feet [2]
- Chronic pain, even at rest [2]
- Bladder and bowel control [4]
- Neurological defects [2]
- Sexual function [4]
- Stiffness in the neck [6]

Nature and Progression

Unfortunately, arachnoiditis is an incurable disease. It has a sudden on set and diagnosis is based on symptoms and Magnetic Resonance Imaging (MRI) [6]. Arachnoiditis symptoms are difficult to distinguish from other diseases [2]. There are no set patterns for those who have arachnoiditis and symptoms vary in severity [1]. Arachnoiditis can reoccur even after successful surgery and if not treated will worsen [2].

Social and interpersonal difficulties

Patients who have arachnoiditis endure chronic pain [2]. This results in many people having a high risk of depression, suicide, and drug and alcohol abuse [2].

Common Psychosocial difficulties:

- Depression [7]
- Anxiety [7]
- Low frustration level [7]
- Irritability [7]

ARACHNOIDITIS
A Toxic Chemical Tragedy

A devastating disease called arachnoiditis is caused by the corrosive action of certain dyes that have been used in spinal X-ray imaging, yet the sufferers are receiving no special treatment or compensation.

by Gil May, CMC, JP, AIMM
©2006
Email: gilmay@qldnet.com.au

Web of deception

Imagine that you have just got out of bed and turned on the TV. You hear that over 100,000 fellow Australians have been struck down with a mystery virus or infection. They are so devastatingly affected that many are in extreme agony, others want to end their life and the rest are crippled.

This is not just another bad-luck medical story. This is a story of deliberate deception by a pharmaceutical drug manufacturer that has sacrificed people's health in the name of corporate profits, with the ongoing approval of the Australian Federal Government. This is an intensely sad human-interest story of a medical chemical that went horribly wrong and whose effects have been hushed up by both the Federal Government which approved it and the pharmaceutical company which manufactured it.

This corrosive chemical is an oil-based acid called Iophendylate. It has been used as an imaging dye that is injected into the spinal canal before spinal X-rays (myelograms) to increase the contrast. It has been sold under brand names such as Pantopaque and Myodil. These dyes have been manufactured and sold by several chemical companies. Pantopaque was manufactured by Lafayette Pharmacal Company, later acquired by Alcon Laboratories, using materials supplied by the Eastman Kodak Company—materials originally designed for use in photographic processing. Pantopaque was approved for experimental use only in Australia between 1974 and 1978. Myodil is a copy of Pantopaque, made by the Glaxo Company between 1945 and 1988 and supplied in the UK and Australia, among other countries. According to a study commissioned by the New Zealand Ministry of Health and released in February 2002, from the 1940s to 1980s there were approximately one million oil myelograms performed each year throughout the world. However, with the advent of magnetic resonance imaging (MRI), myelography with these kinds of chemical dyes is not performed as frequently.

Iophendylate contains hydrochloric and sulphuric acid, potassium permanganate (raw iodine) and benzene (a cancer-causing substance) in an oil base. It causes an excruciating condition known as Arachnoiditis as it migrates throughout the body, causing massive allergic reactions and destroying tissues, nerves and organs, slowly causing death. When the chemical causes the nerves and spinal canal to "fuse" into a conglomerate of mixed-up tissues, nerves and spinal cord, this is called Adhesive Arachnoiditis, and it's the worst and cruellest form of the condition.

Most people have not heard of arachnoiditis—such has been the paranoia of the government and the medical profession. It is one of Australia's greatest shames that patients, with government approval, were injected with this corrosive chemical. The drug Myodil was approved by the Australian Federal Government in 1970 and was used over a period of 19 years from 1970 to 1989.

Can you imagine what this drug did to the patients' bodies? It corroded the spinal cord, nerves and tissues and migrated into the brain and other organs, causing excruciating, ballistic, nuclear hell (as many have described it), paralysis and even death for these innocent victims. Those who died were lucky; the others lived on, wheelchair-bound in intense pain or bedridden and crippled in agony.

The name "arachnoiditis" arises from the sub-arachnoidal space at the bottom of the spine. If you look at a diagram of the human skeleton, you will see at the back of the pelvis four holes on either side where nerves from the legs go up into the spinal canal. It looks like the eight legs of a spider, hence "arachnoid"; and "-itis" is a suffix meaning "inflammation". So arachnoiditis is the result of body tissues and nerves being eaten away by this acid, leaving

scarring or complete destruction of the nerves and tissues. This may occur anywhere in the body as the oil-based acid migrates. These symptoms vary greatly in different people, making arachnoiditis difficult to diagnose, with patients often misdiagnosed as having chronic fatigue syndrome, asthma, motor neurone disease or multiple sclerosis. Sadly, very few people and doctors understand this problem that affects an estimated 100,000 Australians.

When we look at others suffering pain we are sympathetic, but we cannot understand the pain level they suffer. One mother said to me that arachnoiditis was like giving birth to her six children all at once, 24 hours a day for the last 25 years. If you are a mother who has had a difficult time giving birth, you will have some understanding of the pain. Others describe it as a ballistic, nuclear, burning hell; you can be burning and sweating in winter and freezing in summer, trembling and shaking so much that you lose control.

The problem originated with the approval of iophendylate for use in Australia, without adequate testing, provision of test data or safety guarantee required from the manufacturer. The Commonwealth Health Department approved the drug on no proven safety basis.

The US Food and Drug Administration (FDA) only ever licensed the iophendylate drug Pantopaque for *one* use, registering it on 22 February 1944. The chemical formula Pantopaque was thus introduced in 1944, but it was banned in Sweden in 1948, in the United States in 1957 and in the UK by 1990. It was never licensed anywhere else. The manufacturers manipulated this product into hospital use throughout the world on product liability statements which constituted *fraud*, affecting millions of people worldwide. These statements stated the chemical is safe for human use, but hundreds of medical papers now show it is not.

Arachnoiditis patients are often misdiagnosed as having chronic fatigue syndrome, asthma, motor neurone disease or multiple sclerosis.

Iophendylate is corrosive: it dissolves paint, linoleum, rubber, glue, cork tiles and polystyrene coffee cups. Injecting it into people's spinal canals where it corrodes the nerves and spinal cord and wreaks havoc throughout the body and brain is stupidity straight out of a Nazi horror movie. Test your imagination: you are being very slowly cut in half from the bottom to the top with a carpenter's power saw—if that makes you feel a little uneasy and squeamish, you're getting close to what many arachnoiditis sufferers go through 24 hours a day, seven days a week.

Iophendylate came to be used in Australia under what is termed a "grandfathered" agreement, i.e., it is being used in three or more other countries, so it was unlicensed. It was imported into Australia under the Pantopaque brand name between 1974 and 1978, but was approved for *experimental use only*, licensed on a restricted basis to four hospitals. The importer of Pantopaque was licensed to import 150 units; in contravention of the import permit, 13,500 units were imported into Australia.

According to independent researcher Derek Morrison, in June 1978 the Australian Therapeutic Goods Board advised that the company which imported and distributed Pantopaque (allegedly Mr Ernie Hughes) "was involved in unauthorised distribution of the product".

All experiments have procedural requirements to be followed. Where are the signed informed-consent forms of the victims? Where is the experimental documentation? Where are the pharmacology and pathology test results and data sheets? If no pharmacology tests were carried out and if no experimental data were recorded according to medical research procedures, then the manufacturer and importer of this chemical at least committed fraud, for they received financial gain by deception. As there is no statute of limitations on fraud, this fraud must be investigated by the Australian Federal Police and charges laid *now*. The manufacturer must be held accountable for its deceitful and misleading statements on product safety. The law ought to be applied equally without fear or favour or discrimination. Where was the government overview and control of the "experimental use only" proviso?

Adverse reactions ignored in Australia

Following are some landmark findings on the serious adverse effects of iophendolic acid and its component ingredients (for references, see http://www.arachnoiditis.info/content/pantopaque/sarahs_pantopaque.doc):

1928: Odin, Rundstrom and Lindblom (Sweden) published a paper on their findings of acute reaction to iodised oils.

1932: The American Medical Association issued a warning about the long-term risks of introduction of foreign oily compounds into the spinal fluid for imaging purposes.

1938: Mettier and Leake also described adverse reactions to Lipiodol (iodised oil).

1940: Neurologist Eric Oldberg (US) wrote of similar findings.

1930s–40s: Neuroradiologists in Stockholm, working with the famous neurosurgeon Olivecrona, saw patients from all over the world who had previously undergone oil-based myelography and had sustained arachnoiditis as a result; they also had residual dye in the spine and head. It appears that as early as 1935, a decision *not* to use oil-based contrast media was taken by leading Swedish neuroradiologists. Pre-licence studies of the new dye, ethyl iodophenylundecylate (iophendylate), demonstrated chemical meningitis similar to that seen by various authors. Strain and Warren had already conducted animal studies on the new dye, which had originally been synthesised by Plati in 1937–38. These clearly demonstrated that the compound was not absorbed by the body but remained permanently encysted within the spinal column and could thus trigger inflammatory reaction and fibrosis.

1941: Markovich, Walker and Jessico studied the effect of iodised oil on the meninges and published their findings in the prestigious journal *JAMA*. They stated that "after the injection of iodised oil...the oil becomes rapidly encysted by proliferation of the arachnoid membrane".

1952: Erickson et al. published a case report of a fatality after Pantopaque myelography, due to obstructive hydrocephalus.

1953: Schurr et al. described meningeal irritation due to Pantopaque.

1956: An important paper by Davies was published which detailed findings in 124 patients at surgery and up to a year after myelography; 60% showed immediate reaction and 12% developed "chronic adhesive meningitis".

1960: Whilst Taren published a report of raised intracranial pressure and multiple cranial nerve palsies after Pantopaque myelography, labelling was approved by the FDA in America.

1962: Mason and Raaf reported a case of obliteration of the subarachnoid space by Pantopaque-induced arachnoiditis.

These are but a few of the pre-approval scientific medical papers published. Hundreds of other medical-scientific reports of extremely serious adverse (and fatal) reactions to this chemical were published prior to the Australian Federal Government's approval of the chemical for use in Australia. The evidence was so voluminous and overwhelming at the time that the Department of Health cannot claim ignorance of the dangerous consequences of the chemical's use. The Government has a legal and moral obligation to give full recognition to these suffering victims and the dignity of acknowledging their special needs.

The NSW Health Department's Radiology Advisory Committee in its 4 July 1995 report acknowledged that "Myodil is a cause of arachnoiditis, a condition that may result in chronic severe and debilitating pain".

In relation to the dangers apparent in using the chemical, Professor F. J. Palmer, Director of Diagnostic Radiology at the Prince Henry and Prince of Wales hospitals, wrote about Myodil in his December 1994 report: "By the mid-1960s, anyone practising myelography should have been aware of the association of Myodil/Pantopaque [Iophendylate] with arachnoiditis."

Symptoms and diagnosis of arachnoiditis

A great number of medical professionals do not know how to diagnose arachnoiditis, and, in fact, some even deny that arachnoiditis exists. Lack of information prevents the physician from making the correct diagnosis of this disease.

Even the physicians who administer the myelographic procedure do not know all the symptoms and effects of arachnoiditis. When questioned by patients, they may become frustrated and angry. Package inserts which list side effects and toxicity are supplied by the manufacturers and distributed mainly to hospitals and radiology groups. Physicians who treat the problems associated with arachnoiditis are not provided information on the devastating long-term consequences brought on by this contrast medium. Due to time constraints and the fact that much of the data is published in specialist literature, the average physician is poorly informed about the link between iophendolic acid and arachnoiditis.

The disease is often labelled as failed back surgery syndrome (FBSS), lupus, multiple sclerosis, chronic fatigue syndrome, stiff-man syndrome and degenerative disc disease, just to mention a few. Millions of people all over the world who have arachnoiditis are unaware of the cause of their suffering. Proper treatment cannot be obtained because diagnostic criteria cited in medical reports are not readily shared with the medical professionals who treat people with the disease.

Failure to recognise the insidious nature of the disease is a major complication, especially when the symptoms may occur immediately or take years to develop, can be inconsistent and can manifest themselves in many ways. This often results in misdiagnosis with chronic fatigue syndrome, asthma, motor neurone disease or multiple sclerosis.

The symptoms often include impotence in males, limitation of spinal movement, weakness in the legs and a need for regular analgesia. Headache, bladder and bowel dysfunction are common. Burning pain is the significant feature, with one study reporting 96% of patients with lower back pain and 98% with leg pain. *No other disease causes this burning sensation*, which is also reported in the insteps, inner aspects of the knees and in the lumbosacroiliac area. However, arachnoiditis can go undiagnosed for years, and even then may only be diagnosed by excluding all other causes. Arachnoiditis sufferers are often unable to work; the average life-span is reduced by 12 years (although another study stated "by up to 20 years").

Iophendylate is corrosive: it dissolves paint, linoleum, rubber, glue, cork tiles and polystyrene coffee cups. Injecting it into people's spinal canals, where it corrodes the nerves and spinal cord and wreaks havoc throughout the body and brain is stupidity...

Liability of manufacturers

Manufacturers should be financially accountable for all costs incurred by the victims. The Australian Government should be funding litigation against the manufacturers to recover the millions of dollars' worth of medical expenses that have accrued over the last 30 years and will be incurred in the future.

The current compensation system requires the compulsory reimbursement of medical costs before any compensation to the victim is paid. If you win a medical or injury compensation payment, the Australian Health Commission holds your award at its leisure until it searches its files and deducts all medical costs associated with this injury—and then pays you the residual. This often means that the victim receives *no* compensation after the legal fees have been paid. This is bureaucratic nonsense, as it results in lawyers not taking cases they can win because only the medical expenses get paid. These disabled victims are left destitute and unable to fund any attempt for compensation, so they rely on solicitors who do *pro bono* work. Recovery of medical and hospital expenses has been a high government priority and is enforced by specific legislation, so why are chemical companies exempt from paying for the damage their chemicals cause?

Why doesn't the Australian Government hold the same priority with the pharmaceutical companies for costs incurred by the Health Commission? Where is the legislation to recover expenses against these pharmaceutical companies for the injuries sustained from their deadly chemicals which are often used illegally—or is this just another torture for the victim and their families to endure, another ongoing discrimination to bear?

Taxpayers via the Health Commission (Medicare) have to maintain the massive expense of maintaining the lives of these suffering, debilitated victims. Arachnoiditis sufferers often experience the double-whammy of family break-up and they live a life worse than the average dog. You may think this is being overtly descriptive, but not so. It is very blunt reality: just talk to some of the disabled people, as I have. Where is the equality of one law for all?

Manufacturers' reported side effects

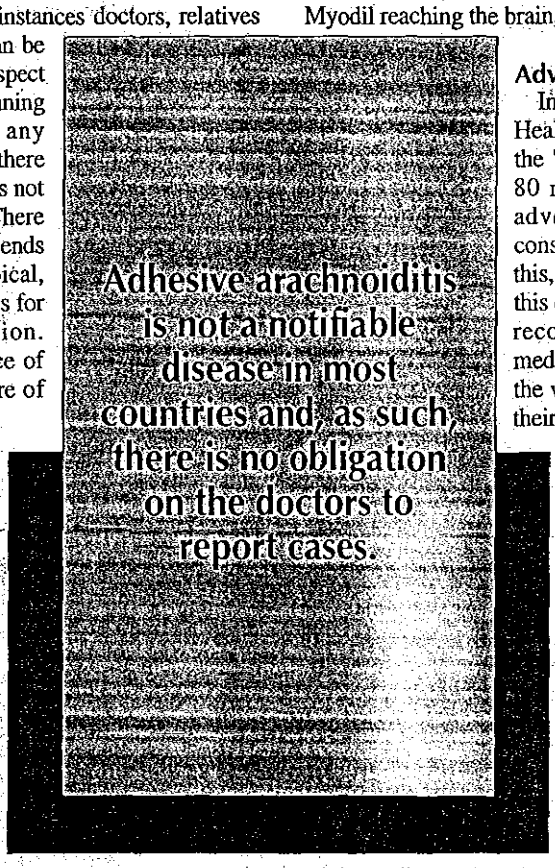
Regarding Myodil, the manufacturer Glaxo's package insert stated: "Acute side effects reported by the manufacturers include headache, backache, neck stiffness, nausea, vomiting, fever and the more serious effect of allergy. An acute aseptic meningitis has been

reported to occur in approximately 0.05% of Myodil cases which is why it is recommended that the agent be removed from the spinal column after examination." Such removal was *never* done in Australia.

The *Australian Adverse Drug Reactions Bulletin* noted the relationship between the retention of Myodil and adhesive arachnoiditis as far back as February 1975.

Arachnoidal reaction in the brain is most prominent around the brain stem, which is significant due to the close proximity to the lower cranial nerves. As explained by Dr I. H. J. Bourne (now deceased) in "Lumbo-Sacral Adhesive Arachnoiditis: A Review", (*Journal of the Royal Society of Medicine* 1990; 83: 262–265, 1990):

"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 'since it is not cancer', 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."



Arachnoiditis pathophysiology

According to Jennifer Owen in her thesis for her Master of Science (Optomology) (University of NSW, June 1998):

"Cranial palsies and late visual effects may arise independently or follow the acute reaction. The contrast agent injected into the lower spine reaches the cranium, as Myodil has been noted on the dental X-rays of patients with chronic headaches and jaw pain. Even after removal of the dye, there is always a small amount of residual dye that can reach the brain.

"Immediate reactions, which are either allergic or vascular, include allergic reactions of the conjunctiva and lids, flickering light and photophobia. Late effects that involve the posterior visual pathways include reduced vision, red-green colour defects, scotomas and cortical blindness.

"Arachnoiditis is characterised by the formation of granulomatous tissue and nerve root adhesions within the leptomeningeal sac. Since the arachnoid and subarachnoid spaces are void of blood vessels, it is expected that the inflammatory reaction arises in the enriched cascularised pia and dura mater. The pia mater is easily traumatised as it is very fragile and sensitive to both chemical and physical injury, and the dura can participate in the production of both dura-leptomeningeal adhesions even without its own direct injury.

"Upon application of a contrast agent, the delicate structure of the arachnoid tissue is invaded by macrophages and covered with a fibrin-like substance. The ensuing inflammation adheres the pia to the dura, obliterating the subarachnoid space. Globules of the contrast agent are often enmeshed in the dense scar tissue. The entangled nerve roots hypovasculate and become progressively atrophic."

Lumbosacral adhesive arachnoiditis is a particularly cruel disease because of the nature of the pain syndrome associated with it, yet its pathophysiology is well understood and is no mystery. The type of pain is uniquely incapacitating, and dolorologists have created the term "regional complex pain disorder" (RCPD) to describe it. (Source: Derek Morrison)

This writer has seen X-ray evidence and a report dated 7 September 1982 (by D. Jones, radiologist at Murwillumbah Hospital, NSW) of Myodil widely dispersed in spinal canals and in "the basal cisterns of the skull", as well as MRI evidence dated 28 March 2006 (from Dr G. Ioannou of South Coast Radiology) of Myodil reaching the brain, "located in the left middle cranial fossa".

Adverse reaction rates

In June 1998, the US National Institutes of Health published "new" findings in relation to the "cause and effect" of iophendylate, listing 80 medical conditions based on reported adverse reactions, many of which can be considered life threatening. Commenting on this, a UK arachnoiditis group noted: "Even at this early stage...it's important to list these, so a record of such 'official, reported' related medical conditions is available to yourself and the wider community, especially sufferers and their loved ones."

It's important to place it on the record that until now the medical profession throughout the world has stated that chemically induced adhesive arachnoiditis develops in "less than 1% of patients" who have previously undergone a myelography with iophendylate.

Furthermore, "it's a very rare phenomena [*sic*]". This statement is not only misleading, it's a lie. In fact, the most current statistical data published shows that the figure is 82.3 per cent. This figure is sourced from the US Food and Drug Administration, the body that originally licensed iophendylate (as Pantopaque).

The FDA's Spontaneous Reporting System, maintained by the Division of Epidemiology and Surveillance, noted on 12 June 1998 that between 1991 and 1995 in the USA, 335 adverse reactions were reported with this chemical. Of these 335 people with adverse reactions, 275 developed chemically induced adhesive arachnoiditis—a reported 82.3% relationship (actually, 82.1%), not the "less than 1% of patients" as currently being touted in the courts by medical bodies.

UK medical researcher S. P. Cunliffe, writing to doctors in 1997, asked: "So why have doctors to date said that adhesive arachnoiditis is a rare condition? The answer to that is very simple. Adhesive arachnoiditis is not a notifiable disease in most countries and, as such, there is no obligation on the doctors to report cases or collect any data recording the number of sufferers. Nor are they reporting adhesive arachnoiditis as a side effect of any drugs used."

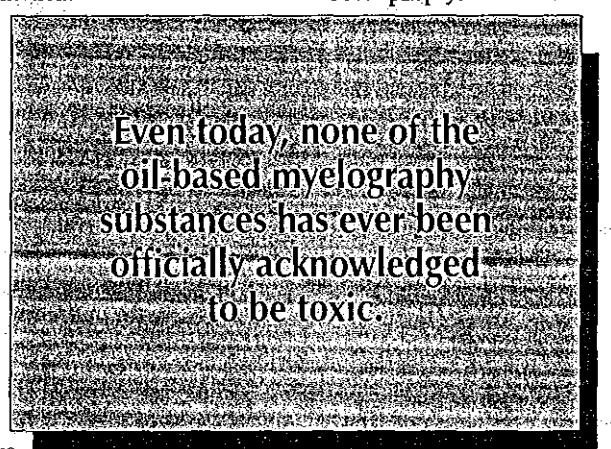
Commenting on the situation in Australia, Cunliffe said: "It's time the Australian Government instructed doctors who see and treat those suffering this disease to report these adverse reactions;

furthermore, getting these same doctors communicating with their colleagues, so when [a patient presents] with apparent related neurological symptoms the patient is sent for an MRI without contrast or Gadolinium. A sufferer of arachnoiditis should *never* be exposed to any further contrast mediums of any kind."

Cunliffe continued: "To correctly diagnose arachnoiditis, it is critical that the MRI machine is *not* set on the current settings that use water-based contrast mediums, but set for the *positive* for this oil-based contrast medium (chemical) that was used on the patient many years earlier. Until this is done, a 'false' report of 'limited severity' will continue. Once an MRI has been done using these 'old' settings, a patient must then have a full Nerve Conduction Test of all limbs including VERs.

"Adhesive arachnoiditis is not just a dirty word, as some medical professionals describe it. Arachnoiditis is a disease which destroys the lives of many human beings and their families. We ask doctors to help us find an effective form of treatment, or even find a cure for this disease, and do your level best to prevent others from contracting this 'horrific' debilitating condition."

An estimated 100,000 or more Australians are suffering from this cruel, incurable condition (although a senior government medical officer told one arachnoiditis sufferer in Victoria that the figure for victims of the "blue dye" is more likely to be 350,000). Most annoying to the sufferers of arachnoiditis is that the symptoms have all too often been dismissed as "psychosomatic". However, the contemplation of suicide by these victims is all too frequent and is *real*: death is preferable to a lifetime of agony.



Medicine is practised on a "risk versus benefit" basis, so how can it be carried out if the doctor is deprived of appropriate information or is ignorant of the risks? How can the patient give "informed consent"? One doctor told me that if you had Myodil dropped into your eyes, you would lose your sight.

X-ray contrast agents

The following quote is from US radiologist and neurological specialist Dr Ken Giles. It is taken from a newsletter produced by researcher Derek Morrison (bracketed sections are added for the reader's understanding):

"[Arachnoiditis] is but one of the many lesions caused by X-ray contrast agents, as a glance into the publication *Martindale's Pharmacopoeia* will demonstrate. Indeed, the arachnoiditis caused by oils is quite different from water-soluble agents. The oil Myodil [and Pantopaque] causes adhesive arachnoiditis as the result of the oil globules, particularly those which lodge in the nerve root pockets for long periods. The oil is slowly eliminated at the rate of 1 mL/year [this is currently being disputed, as X-rays show a 65 mm column of the oil-based acid still in the spine and globules in the brain 34 years later]. During this time fibroblasts, in a futile attempt to seal off the irritant, secrete collagen which invades and destroys the nerve roots: the result is paralysis of the muscles served by the spinal nerve, which [currently] is untreatable. On the other hand, the later-developed water-soluble agents did not (it was said) cause arachnoiditis. We now know that this is not so.

"If the agent is injected at a hypertonic concentration [hypertonic means "a solution that has a greater osmotic pressure than another solution", in this case cerebrospinal fluid], the osmotic shock induced can cause arachnoiditis. However, the agent intermingles with the cerebrospinal fluid and in a few days is eliminated in the urine. However, extensive diffuse scarring results but without adhesion to the nerve roots. There is no paralysis but extensive, sometimes all-body pain is permanently induced, particularly by Metrizamide [known also as Amipaque for those retired professors of radiology in Australia who have "selective memory"]. It is known that the water-soluble agents enter the central nervous system, particularly the cerebrum, prior to elimination. The consequences are an increased rate of nerve cell death accompanied by a plethora of neurological deficits from psychosis [meaning one of a group of mental disorders that feature loss of contact with reality] to grand mal [major epileptic attack with loss of consciousness]."

Dr Giles further stated: "...it seems that because Metrizamide does not contain sugar, when it enters the central nervous system it begins to destroy the sugars that are present there. That means that the brain becomes starved of oxygen, and so cell damage occurs, as does epilepsy."

It is noteworthy that even today, none of the oil-based myelography substances has ever been officially acknowledged to be toxic. Because Myodil dissolves rubber, glues, linoleum, paint, cork tiles and some plastics, surely this must have made some of the medicos question its suitability? How many brain cells are needed for a doctor to realise that any foreign, corrosive, oil-based chemical injected into the spine must cause unbelievable problems?

This is the body's main nerve centre.

Derek Morrison has made available a 40-page history from 1938 to 2000 of adverse findings (with 13 pages of reference footnotes) against Pantopaque. The research documents how the drug caused arachnoiditis and it provides evidence of neurotoxicity, cysts, associated syrinx (fluid-filled cavity in the spinal cord) resulting in progressive spastic paraparesis (paraplegia), chronic focal seizure, encephalopathy causing post-operative convulsions, blindness, granulomatous meningitis in the brain and spinal cord, etc.

In Australia the manufacturers and importers of Iophendylate misled everybody with their product safety statements, acting without guilt and indiscriminately destroying people's lives in the name of profit. So why hasn't the government done anything to help these victims? Why hasn't it sued these companies for the millions of dollars in medical costs incurred by Medicare—that you, the taxpayer have paid for?

Myelography and Myodil in Australia

Concerning Myodil, it should be borne in mind that the manufacturer:

1) conspired not to supply complete and forthright animal and clinical data regarding the risks of injection of Myodil into the subarachnoid space for myelography to the Australian Department of Health and the medical community;

2) failed to provide adequate and truthful information to the Department of Health, the medical community and the Australian public in official documents, labelling, product promotions, and written and oral communications while downplaying the severity of adverse events and risks;

3) knowingly marketed a product to the Australian public via prescription by physicians while not providing those physicians with adequate information regarding potential risks and benefits;

4) knowingly marketed a product that could be dangerous to physicians when it was aware that Myodil is toxic to animals and humans when injected into the subarachnoid space and is associated with granulomatous meningitis, severe progressive obliterative arachnoiditis, adhesive arachnoiditis, paralysis, seizures, bladder and bowel dysfunction, coma and even death;

d) placed corporate profits from sales of Myodil over legal responsibilities and obligations to ensure the safety of its product for the Australian public (such irresponsible and dangerous actions by the manufacturer prior to 1970 directly contributed to the pain and suffering of the Australian public exposed to Myodil and directly contributed to the Australian healthcare burden via Medicare).

As for the drug itself:

1) Myodil is not water soluble and remains primarily unabsorbed in the body;

2) Myodil histologically has been shown to trigger a severe granulomatous foreign body inflammatory reaction;

3) Myodil injection into the subarachnoid space for myelography has been acutely associated with producing symptoms of aseptic and chemical meningitis, fever, shock, respiratory arrest, coma and death.

4) Myodil myeolography has been associated with severe, chronic adhesive and obliterative arachnoiditis, progressive neurological deficit, paralysis, focal and grand mal seizures, blindness, cauda equina syndrome, obstructive hydrocephalus, chronic pain, shock, coma and death.

5) Myodil injection carries both significant and severe acute and long-term risks for the patient beyond the risks of routine lumbar puncture.

6) Myodil studies on human hypersensitisation have never been conducted.

Why haven't the chemical companies and the drug manufacturers and importers been charged for the cruel suffering that their chemical has inflicted upon so many innocent people?

The cost of fraud

Why are chemical companies exempt from premeditated fraud, costing our Health Department billions of dollars of taxpayers' money? Why haven't the chemical companies and the drug manufacturers and importers been charged for the cruel suffering that their chemical has inflicted upon so many innocent people? Why haven't they been charged with fraud over their dishonest and false product liability statements and for breach of their "experimental use only" approval criterion, knowingly allowing a dangerous substance to be administered in a medical procedure?

Historical data show that the manufacturers were well aware of the dangers associated with this insidious chemical, so their continued marketing and supply constitutes a premeditated, deliberate act of assault upon the people of Australia.

If an individual deliberately caused any one of these injuries, he or she would be charged, tried and imprisoned; there would be great outrage and compensation to the victims. What are we going to do about these insidious chemical companies that knew more than 30 years ago that their chemical caused arachnoiditis?

Recognition is given to those suffering from chronic fatigue syndrome, asthma, cerebral palsy, motor neurone disease, multiple sclerosis and diabetes, but myelogram-induced arachnoiditis sufferers are ignored. Why?

The Hon. Jenny George, MHR, Member for Throsby, moved a private member's bill in Federal Parliament on 16 September 2002, calling for a full independent inquiry. The government defeated it and had it thrown out. Why? Because the Australian Federal Government approved and supported this insidious chemical attack upon its own citizens and has deliberately ignored the victims' plight ever since, while protecting the chemical companies and refusing to prosecute them for their chemical war on medical patients.

The disrespectful manner in which the Australian Government has treated these unfortunate people, whose only crime was not knowing the right questions to ask before a "minimally invasive" myelogram or epidural steroid injection was performed, has been desperately sad to see.

A request for a parliamentary inquiry from every reader is the only way there will ever be recognition and justice for these victims. Would you please give this your support and write to your Federal Member of Parliament and tell him or her that you refuse to vote for them if they do not promptly hold an independent inquiry.

It is time to show the same level of concern for our fellow Australians that we showed for the tsunami victims.

This is the story that must be told. Please tell this story to everyone and help get recognition for the victims.

∞

Acknowledgements

Special thanks go to the following people who assisted in the preparation of this article:

• Derek Morrison (derek.morrison@redback.org.au), who provided much information and direction. Derek single-handedly started the fight for Australian sufferers at great expense and sacrifice to himself, spending years giving help, hope and comfort to so many sufferers who were isolated with nowhere to go—exactly what was denied to him. Derek, like so many others, is the victim of a very unjust legal system. Thanks, Derek, and best wishes.

• Dr Sarah Smith from the UK's National Organisation for Healthy Backs. See her 2002 article "How the Dye was Cast: Shedding Light on a Dark Industry" at http://www.arachnoiditis.info/content/pantopaque/sarahs_pantopaque.doc.

About the Author:

Gil May is a farmer's son from Won Wron, Gippsland, Victoria, with varied experience in engineering-related areas as well as business management and industrial relations. Thirty-four years ago, working as a power station senior operator, he suffered a back injury and was given a myelogram without any advice on potential side effects. Unable to obtain answers about his symptoms, he conducted research and discovered that his X-rays showed residual traces of Myodil. He has since been communicating with other sufferers of the chemical's dire side effects.

Gil May can be contacted by email at gilmay@qldnet.com.au.

References

• Australian Arachnoiditis Sufferers QLD Association, http://www.aasqa.info/members/AASQA-Members.htm
• The Burton Report: http://www.burtonreport.com
• Suzanne Perisian, MD, report dated 30 March 2002 at http://www.burtonreport.com/InfSpine/AdhesArachParisianReport.htm
• Mike Feehan's website http://www.arachnoiditis.co.uk/, email contact@arachnoiditis.co.uk

MAY 5TH, 1982.

Airman wins historic compensation judgment

The Australian

FOR the first time, Australian servicemen injured on duty in peacetime have been guaranteed the right to damages compensation from the Government.

In an historic judgment delivered yesterday, the full High Court gave servicemen the same legal rights as civilians, who can sue their employers for compensation if they are injured at work.

About 73,000 people are employed in Australia's regular armed forces.

A spokesman for the Defence Department said the

By MARSALI MacKINNON

High Court decision made the rights of service personnel "legally watertight".

He said that since the Voyager naval disaster in the mid-1960s, when the rights of servicemen to compensation were last formally tested, the Commonwealth had in fact paid out "millions of dollars in hundreds of cases" where defence personnel had been injured outside combat.

"But the rights of servicemen were in doubt until today," he said.

"Some Supreme Court judges were still knocking back compensation claims brought by servicemen against the Government, and the Government took this case to the High Court to have it settled once and for all."

The test case, heard last September by the High Court, involved an RAAF airman, Peter James Groves, 35, who was injured while on duty in Mt Isa in 1973.

Mr Groves was one of the crew of an RAAF plane on a "VIP" flight to the Northern Territory.

The accident happened at Mt Isa airport, when Mr Groves left the plane via a rope ladder which had not been properly secured.

He fell to the ground, injuring himself.

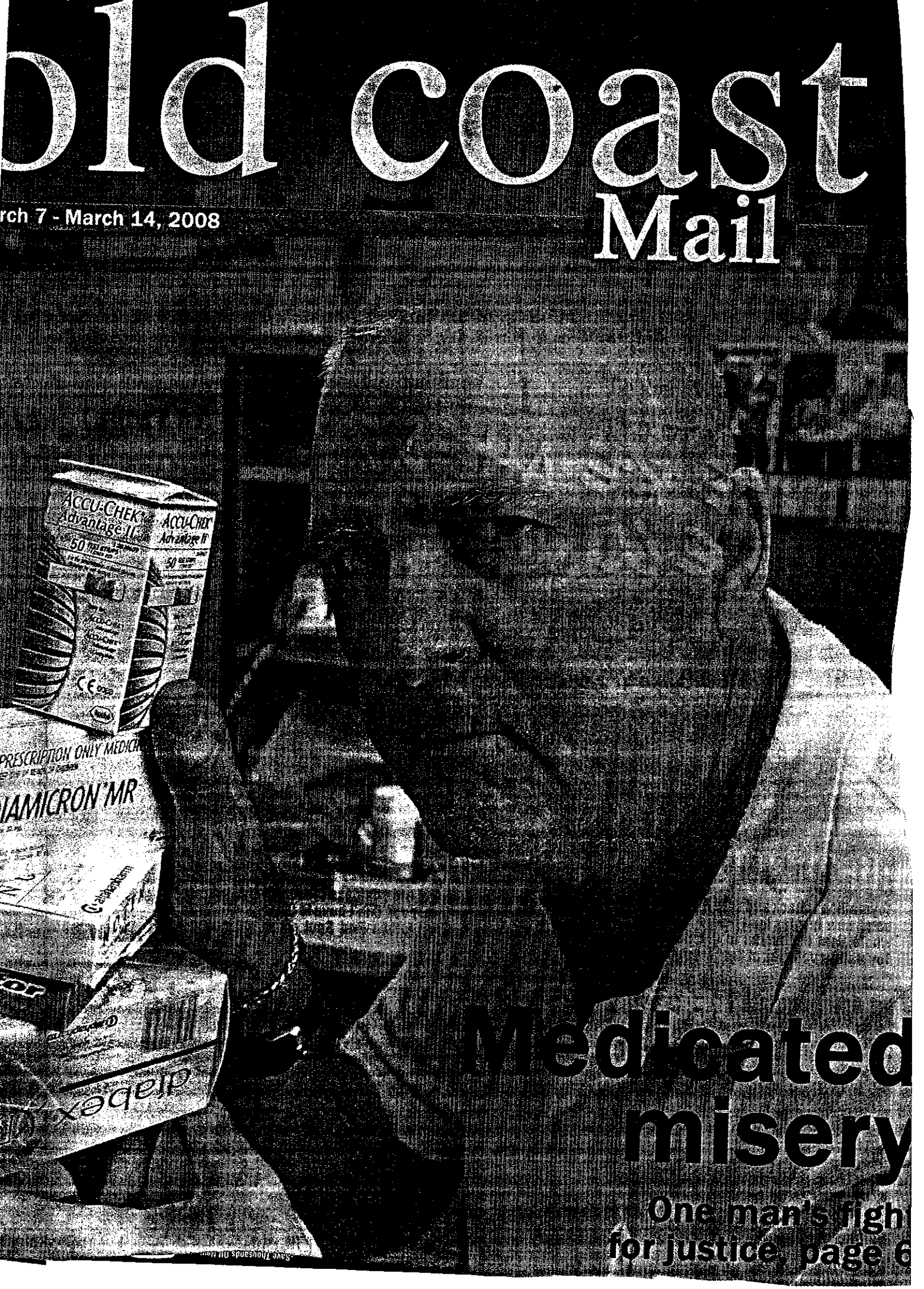
Mr Groves began an action for damages against the Commonwealth in 1979 "arising out of the negligent acts or omissions of a fellow member of the Armed Services whilst on duty".

The Chief Justice of the High Court, Sir Harry Gibbs said in his judgment Australia's military codes "did not deal with the duties of members of the armed forces to each other as citizens".

Handing down their judgement, Justices Stephen, Mason, Aickin and Wilson said this effectively placed a serviceman "outside the protection of the common law".

old coast Mail

rch 7 - March 14, 2008

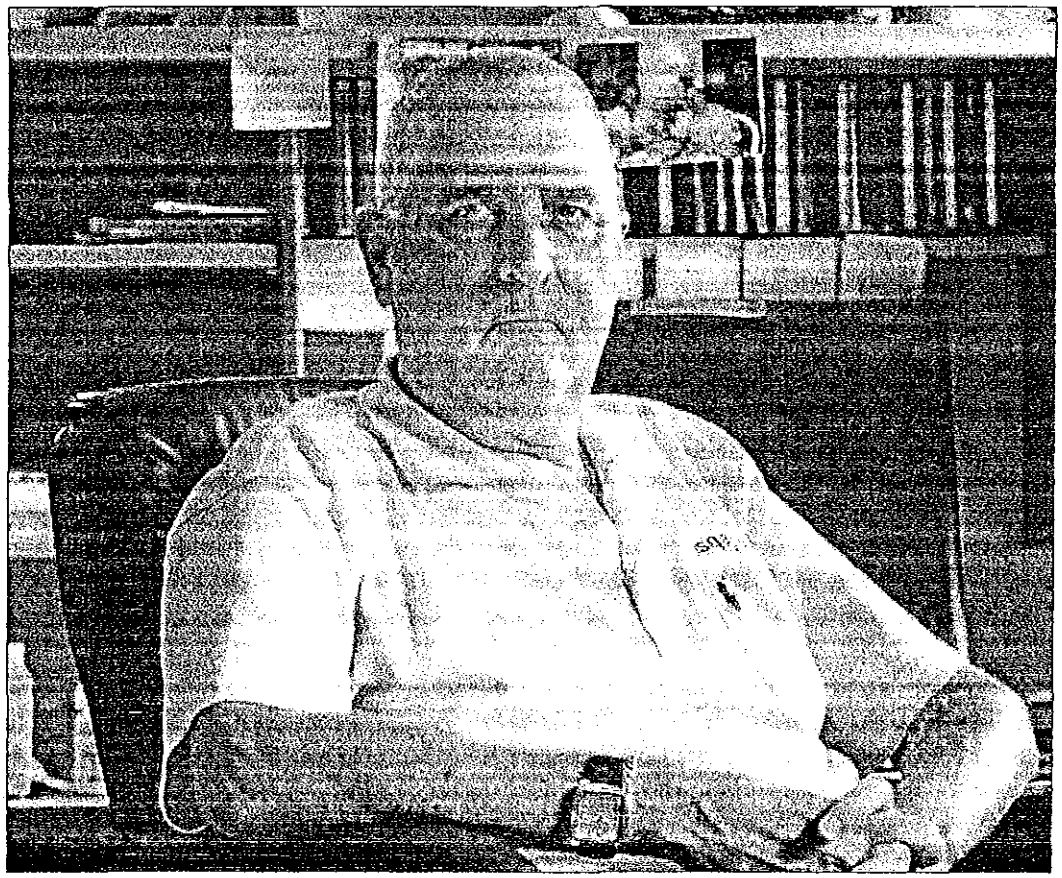


Medicated misery

One man's figh
for justice, page 6

Cure worse than cause

From a high-flying career serving international dignitaries to a bleak future that will end in permanent disability was the strange twist of fate for Peter Groves, as **Leonie Brann** reports.



PETER Groves says he is permanently disabled after a procedure to cure him of an injured spine only made the problem worse and he now awaits a painful death because of it. D1037408

PETER Groves doesn't know what life will offer him from one day to the next – and while that is life for all of us, for the Palm Beach resident each new day can bring more pain and even paralysis.

"Some days I wake up and can't get out of bed, other days I'm feeling good and can get about doing things," said the former RAAF VIP aircraft steward.

"Having the condition that I have is like having a life sentence hanging over my head, and my condition is the result of medical intervention."

The 60-year-old grandfather is one of more than 350,000 people who are registered with Centrelink as permanently disabled after suffering horrendous and wide-ranging side effects from the use of a "toxic blue dye" during specialised X-ray procedures between 1945 and 1987.

After a long battle, Peter, who had five investigative procedures using these dyes that he says were never approved for widespread use by Commonwealth medical watchdogs, the Therapeutic Goods Administration (TGA), has been diagnosed with adhesive arachnoiditis – a condition that causes more than 80 different side affects, from elevated blood pressure and sugar, to cancer, shortened life expectancy and permanent disability, then finally a painful death.

"I'm a 60-year-old that looks like an 80-year-old because of the muscle wasting," Peter explained.

"The constant pain is unbearable and has been described by one other sufferer as having a nuclear holocaust erupting underneath your skin.

"The TGA only approved four hospitals in Australia to use these dyes, but between the 1940s and 1980s, until the dye was banned in 1987, about one million people in Australia had myelograms that where performed with this dye.

"When they put in the dye they remove some of the spinal fluid and replace it with this chemical. Research shows that the dye never leaves the body and there is no known cure, so basically it's a death sentence.

"The oil in the dye does not dissolve but pools at the base of the spine in the arachnoid spaces of the spine where it melts the nerves.

"About 80-90 per cent of people who have had a myelogram will end up with arachnoiditis symptoms, and 10 per cent of people die from the use of the dye.

"The ingredients of the dye include: iodine, benzine (petrol), hydrochloric acid, sulphuric acid and sodium permanganate, which melts holes in rubber.

"The problem is that not many people were told about the side effects of the dye, and would not know that they have the condition because it can take up to 20 years for the symptoms to appear."

Facing a future in a wheelchair, due to a lack of sensation and reflexes in his legs below his knees, was the last thing on a young Peter Groves mind when he joined the Air Force in search of a challenge and adventure.

After completing a special training course with Qantas, Peter joined the crew of stewards who accompanied the Prime Minister, his cabinet and special dignitaries on trips both domestically and internationally.

It was during his maiden flight in July 1973, travelling in rural Queensland with a then Minster of the Whitlam government, that tragedy struck a young man in his prime.

While disembarking a hangered aircraft, Peter crashed to the hard ground below onto his back after a folding set of stairs not securely attached to the plane gave way.

Peter continued working after the accident before he had his first spinal surgery when his first myelogram was performed, until crippling pain led to his being discharged from the defence force in 1975 as medically unfit but without a pension because it was believed his symptoms where psychosomatic.

A landmark court battle ensued in which Peter won the right to be declared totally and permanently disabled, and now receives a pension as he can no longer work.

"My time with the RAAF was amazing," Peter remembered.

"I got to meet then crown prince of Japan, who is now the emperor and got to go to Cambodia for the coronation of the new king and queen.

"I never would have thought that my dream job would have led to this," Peter said running his hands down his fithe, six-foot frame.

With a lack of expertise on the condition, and even some doctors being dismissive of the condition, as well as some research suggesting modern MRIs where a contrasting dye is used as well as common-place epidurals used during childbirth, could lead to adhesive arachnoiditis, Peter says the medical fraternity and governments need to be held accountable.

To fight for the natural justice of sufferers Peter formed the Adhesive Arachnoiditis Sufferers Queensland (AASQ) support group, which now has members both here and overseas.

"This is the biggest scandal of the 20th century, other countries have banned its use – in Sweden it was banned in 1983 – but in Australia we kept on using this toxic dye until 1987," Peter exclaimed angrily.

The AASQ will hold its annual general meeting on Wednesday at the Currumbin-Palm Beach RSL from 10-noon.

For more information on adhesive arachnoiditis visit www.theaword.org or call Peter Groves 0428 356 655.

Surgeons knew risks in spine dye

By ANNA PATTY
Health Reporter

AUSTRALIAN neurosurgeons were aware that a dye injected into the spine for X-rays could cause chronic pain, the head of the NSW Neurosurgical Association said yesterday.

Association president Warwick Stening said experts believed the benefits outweighed the risks.

The controversy over the dye, marketed as Myodil and used in an X-ray called a myelogram from 1945, was revealed by the *Daily Telegraph* yesterday.

The dye was a huge advance in its day and was widely used until the 1970s because it gave doctors the ability to diagnose life-threatening spinal conditions accurately for the first time.

Spinal compressions due to disc ruptures and tumours were previously identified through physical examination and exploratory surgery.

"When it was introduced it was held to be a big advance because for the first time you could diagnose spinal compressions which allowed for the accurate planning of surgery," Dr Stening said.

"It was known it [the dye] could cause irritation and scarring in the long term around the nerves in the spine in some patients and that this could cause chronic pain. But there wasn't anything else and the alternative was to leave people in extreme agony.

"It was replaced as soon as the technology was available to do so."

It was replaced by water soluble dyes from the 1970s.

Dr Stening said myelograms were later replaced by CT scans and magnetic resonance imaging (MRI) technology, which were regarded as effective in diagnosing spinal conditions by the mid-1980s.

He said another dye called Thoratrast, containing radioactive thorium sulphate, was used in the 1930s and 1940s for X-rays inside the head.

It was later found to cause cancer before being replaced by Myodil and other agents.

"It's part of the evolution of this type of technology," Dr Stening added.

NSW Health Minister Craig Knowles yesterday said it was the Federal Government's responsibility to regulate quality and safety of medications.

He said he would back a review of the Myodil issue.

But a Federal Health Department spokeswoman said no investigation was necessary, adding: "It hasn't been on the market for 20 years or so."

Q & A

Q What are Myodil and Pantopaque?

A Oil-based chemical dyes that were injected into a back before an x-ray to make it easier to diagnose certain back problems.

Q Are they still in use?

A No. They were used in Australia between 1945 and the late 1980s and have been replaced by new technology.

Q What is arachnoiditis?

A A painful condition caused by inflammation and fusion of nerves and membranes in the spinal chord.

Q What are its symptoms?

A Victims suffer a range of symptoms including burning back pain, incontinence, visual defects, seizures and paralysis.

DAILY TELEGRAPH · 2002

30th JULY ~~OF AUGUST~~.

Spinal patients kept in the dark

Dye side-effects not mentioned

By SUE DUNLEVY

IT was not standard practice to warn patients about the possible complications of injecting dye into their back before an X-ray, according to the Royal Australian College of Radiologists.

Associate Professor James Roche, a radiologist at Royal North Shore Hospital, said doctors who used the dye were not negligent even though some believed it could result in severe complications in a small number of cases.

The claim came as victims, who suffer chronic back pain, seizures and incontinence, demanded a public inquiry.

Other radiologists considered the dyes were completely safe, he said. "They were doing in good faith what they had been taught, what was common standard practice around them," he said.

If radiologists had warned patients the dye might cause arachnoiditis, a painful condition caused by inflammation and fusion of nerves and membranes in the spinal cord, "they wouldn't have understood the implication", he said.

The Daily Telegraph revealed on Monday that two oil-based dyes, Myodil and Pantopaque, had been linked to the debilitating condition known as arachnoiditis.

The condition leaves sufferers in chronic pain, suffering from incontinence, visual defects and seizures. "In retrospect, some may consider this attitude was incorrect," Professor Roche said.

Professor Roche, who has written several papers on arachnoiditis, said there were about 30 different causes of arachnoiditis, the most common being back surgery and patients who had "had some form of injection in their back".

He said the dye was the only way radiologists could diagnose certain types of back problems between 1945 and 1978.

It was then replaced by water-soluble dyes and later by CAT scans and magnetic resonance imaging.

Professor Roche said one of the water-based dyes, Metrizamide, had been found in animal tests to cause inflammation in concentrated doses.

But the Therapeutic Goods Association said it had received only one report linking the new water-based dyes to a suspected adverse reaction.

The Daily Telegraph has been deluged with hundreds of telephone calls from people who had a myelogram X-ray using the dyes, and who believe they are suffering complications from the procedure.

Many of them claim their doctors cannot explain what is causing their pain.

Put an end to the buck-passing for people in pain

COMMENT

BY SUE DUNLEVY

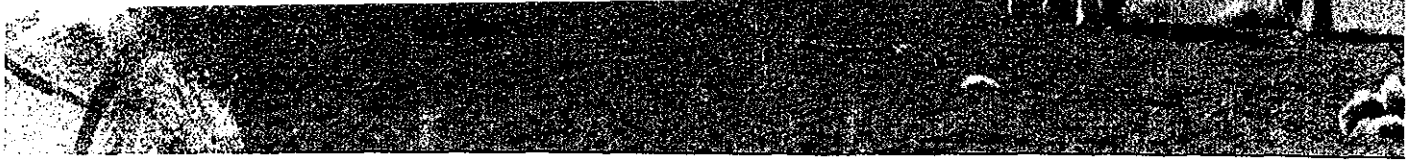
RADIOLOGISTS knew it, the body charged with checking drug safety knew it, but no one told the patients the dye injected into their back was linked to chronic pain.

Hundreds have contacted *The Daily Telegraph* with horror stories about the pain they are living in after having a myelogram X-ray. In many cases their doctors have been unable to explain the cause of their pain.

Some of these people are wheelchair-bound, bedridden for long periods and can survive only on doses of morphine, pethidine and methadone.

They want recognition. The Federal Government must inquire into the extent of a problem which has been swept under the carpet for too long.

If you are a victim contact:



Bill Finlayson's Brewarrina property the only food his remaining 1800 sheep are getting is pellets.

Getting drier: only the state is not in d

By MARK SCALA
Regional Reporter

MORE than 80 per cent of NSW has now been drought declared as the State Government increases the number of farmers eligible for assistance.

This comes as climatologists warn an El Nino expected to grip the nation until next year will be worse than the last time it hit in 1997.

Only 8 per cent of the state is not considered to be in drought, with the remainder marginal, as NSW's entire winter cereal crop is threatened.

The opportunity for farmers to plant a crop in the state's north has already closed — and if rain does not fall in the next two weeks the southern grain belt will also miss out.

Agriculture Minister Richard Amery will today announce that farmers who have been in a drought declared region for more than six months will receive immediate aid, including subsidies for stock fodder and water.

Under the subsidies farmers will be eligible to receive up to $20,000, an increase of $5000 on the old transactional subsidy system.

Originally only those who were in drought for 12 months were eligible for limited assistance — however the State Government has reassessed its criteria as conditions deteriorate.

As the drought continues, more areas will be added to the list under the six-month criteria with ongoing assessment of the aid package.

According to the report 82 per cent now in drought, a per cent from last

The NSW Farm yesterday called fo farmers likely to l crops as a result of

Farmers Associ Mal Peters said pleased with the Gc port — but warned the drought breaks crops will continue

One of the first t the new assistan Finlayson who, decent rain at Br November 2000.

By the end of last down to just 1800 s to the 3000 he usual

As waits for the has been forced to s sheep pellets, whic "be enough to keep

Criteria for assistance to farmers

❑ **Graziers** and farmers who live in an area where more than 50 per cent of the Rural Land Protection Board has been in drought for more than six months.

❑ **This** includes Bourke, Brewarrina, Broken Hill, Cobar, Coonamble, Coonabarabran, Kempsey, Milparinka, Nyngan, part of northern New England, Walgett, Wentworth, Wanaaring and Wilcannia.

❑ **The** help includes 50 per cent subsidies for transport of water and stock.

❑ **Subsidies** will be capped at $20,000 a year for each farm, plus $5000 for water transportation.

Spinal risks recognised

By SUE DUNLEVY

A SENIOR radiologist has admitted he was aware of 10 patients who developed a cavity in their spinal cord after dye injections before an X-ray.

And he has advised patients who are referred for this type of X-ray, known as a myelogram, to ask their doctor whether another diagnostic procedure could be used.

Royal North Shore Hospital radiologist Associate Professor Jim Roche plans to submit a research paper studying the effects of myelograms to a medical journal later this year.

And he believes there is an argument that a large-scale study should be conducted into the effects of myelograms. Australian Medical Association vice-president Dr Trevor Mudge has also called for an investigation into the effects of the procedure.

How the *Telegraph* broke the story

The Daily Telegraph revealed last week the oil-based dyes Myodil and Pantopaque used in the X-ray procedure between 1945 and 1987 have been linked to a painful and incurable condition known as arachnoiditis which may take years to develop.

Radiologists knew of the risks but did not routinely warn patients they could develop this condition, which inflames the membranes surrounding the brain and spinal chord.

Professor Roche said he had studied 980 patients who had myelograms carried out before 1978 and found X-ray evidence that 81 had developed arachnoiditis.

The condition was associated with Myodil in 60 patients, although some patients did not report symptoms of the condition.

The Royal Australian College of Radiologists yesterday issued a position paper on myelograms in which it conceded that "we can't escape the fact that harm may have been done to some people".

But it said the dyes were the only method of diagnosing problems in the spinal cord until 1978 and studies showed the risk of complications was less than 1 per cent. Professor Roche said his argument for a study was not the position of the RACR.

Speaking for the college he said there was debate about whether myelograms could be linked to reactions such as arachnoiditis.

Bodies found after boat trip

THE bodies of a man and a woman have been recovered on the south coast after a boating trip turned to tragedy.

The couple, in their 50s, left Basin View, near St Georges Basin, about 8.30am on Tuesday in a 5m aluminium boat, a police statement said yesterday.

They were reported missing by their

Treed moggie saved

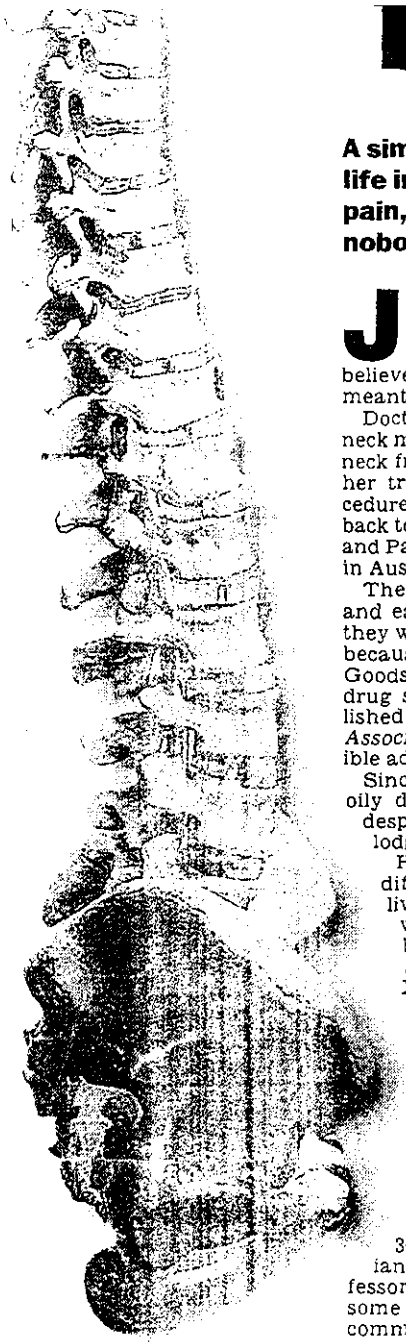
A CAT stuck up a tree for two days was finally rescued by a good Samaritan tree lopper yesterday.

The cat, believed to be a stray, was spotted at the top of a turpentine tree in Daisy St, Revesby, early on Tuesday morning.

On Wednesday morning Bytecan office manager Deborah Rose called the NSW Animal Welfare League, who came out to check.

Police and fire brigade were called but powerlines near the tree meant they were unable to climb up and rescue it.

Toxic treatment



A simple injection turned a ballerina's life into a nightmare of excruciating pain, SUE DUNLEVY reports, yet nobody will admit their mistake

Jenny Carter's training as a classical ballerina saved her life in a car accident 27 years ago, however the injuries she suffered were nothing compared with those she believes were caused by the medical treatment meant to help her.

Doctors told her it was the sheer strength of her neck muscles that saved her life and prevented her neck from snapping in the accident. But as part of her treatment Carter had a myelogram, a procedure which involved a dye being injected into her back to highlight it for an X-ray. Two dyes, Myodil and Pantopaque, were used in the X-ray procedure in Australia between 1945 and the late 1980s.

They are toxic enough to melt polystyrene cups and eat the surface of linoleum floor tiles, but they were never tested as safe to use in humans because they were in use before the Therapeutic Goods Administration, the body which checks drug safety, was set up. A medical study published in the *Journal of the American Medical Association* in 1945 warned doctors about possible adverse reactions to Pantopaque.

Since the day she received the injection, the oily dye has travelled up Carter's spine and, despite repeated attempts to remove it, it is lodged in her brain, behind her eye socket.

Her balance is so disturbed she finds it difficult to drive or watch television and she lives with excruciating pain in her back, which she says feels like broken glass and burning. "Wherever the dye is lodged in my spine I get excruciating pain and when an X-ray is done there is a blob of dye where the pain is," Carter says.

The 58-year-old from Gladesville is one of hundreds of people who have contacted *The Daily Telegraph* since we exposed the link between myelograms and a painful condition called arachnoiditis — a painful inflammation of the nerves in the spinal cord. Its symptoms include a burning pain and it can result in blurred vision, incontinence, seizures and, in some cases, paralysis. There are about 30 causes of arachnoiditis but Royal Australian College of Radiologists spokesman, Professor James Roche, says spinal surgery and some form of back injection are the most common causes.

There is no cure and doctors can only offer the sufferers pain relief, including morphine, metha-done and pethidine. Carter's marriage broke up because of the pain she suffered and an afternoon with her four grandchildren leaves her bedridden with pain for several days afterwards.

"I used to race yachts and now I can't stand on a pontoon without losing my balance. Sometimes I just wish I had died in that car accident," she says.

Sweden banned the dyes in 1948 because of concerns over their toxicity. In 1956, British medical journal *The Lancet* published a study of 119 patients injected with Myodil which found chronic symptoms in 14 patients. In nearly half the patients, the dye had worked its way into their skull. In the 1960s, the drug company Lafayette began developing a half-strength version of Pantopaque called Pantopaque II. Comparative tests carried out on dogs found virtually all dogs suffered inflammatory reactions and although the new dye was abandoned, the original full-strength version remained on the market.

In February 1975, Australia's *Adverse Drug Reactions Bulletin* reported it had received more than 400 reports of reactions to a variety of contrast agents in the previous decade.

Seven instances of fatal reactions were described. Eight of the reactions were to Myodil and Pantopaque and two of these reactions were catalogued as arachnoiditis. Yet the dyes continued to be used in Australia until the late 1980s.

The Royal Australian College of Radiologists says its members were aware of the dangers of using these dyes but says the complications were rare and the procedure was the only method of diagnosing severe back problems until 1978.

Although those carrying out the procedures knew the risks of using the dyes, it was not standard practice to warn patients about the dangers. They wouldn't have understood the implications, a spokesman for the college says.

Hundreds of people now believe they understand the implications. They believe these X-rays have left them crippled with pain and living in a rollercoaster of hell, as Jenny Carter describes it.

Many of those who think that way are frustrated their doctors cannot or will not explain the source of their pain. Some have been told by doctors the dye is the cause of their agony but complain the doctors won't put this in writing because they don't want to blame their colleagues.

A specialist at Royal Prince Alfred Hospital once told Carter the Myodil was the source of her problem but nobody's ever put it on paper, she says.

Drug company Glaxco Smith Kline, which owns Myodil, claims there is no conclusive evidence that the dye causes arachnoiditis.

The company has reached out-of-court settlements with more than 400 people who had myelograms in Britain and 130 in Australia but does not admit liability. By 1998 the US Food and Drug Administration had on record 335 reports of adverse reactions to Pantopaque; 275 of these reactions were the development of arachnoiditis.

The Therapeutic Goods Association, which monitors the safety of drugs used in Australia, is refusing to hold an inquiry into the link between the dyes and arachnoiditis. They claim the complications were well known and there is no present danger because the dye was withdrawn from the market in 1987. But the hundreds of patients whose chronic and debilitating symptoms have been fobbed off as arthritis or unexplainable see this as the continuation of a conspiracy that has kept them in the dark about their condition. "They're waiting for us all to die," one victim says.

Dyes' devastating powers

Dyes called Myodil and Pantopaque were injected into patients' spines in X-ray procedures called myelograms, from 1945 to 1987. Their toxicity is such that polystyrene cups (pictured) and linoleum floor tiles disintegrate when the dyes touch them.

Myelograms have been linked to a painful condition called arachnoiditis — an inflammation of the nerves in the spinal cord. Symptoms include a burning pain and can result in blurred vision, incontinence, seizures and sometimes paralysis. There is no cure.

Medical studies overseas warned about the possible adverse reactions to Pantopaque as early as 1945 but the dyes were never tested in Australia before being put to use.


Exclusive: 42-year medical cover-up exposed
SPINE CHILLING

How *The Daily Telegraph* broke the tragic story last Monday

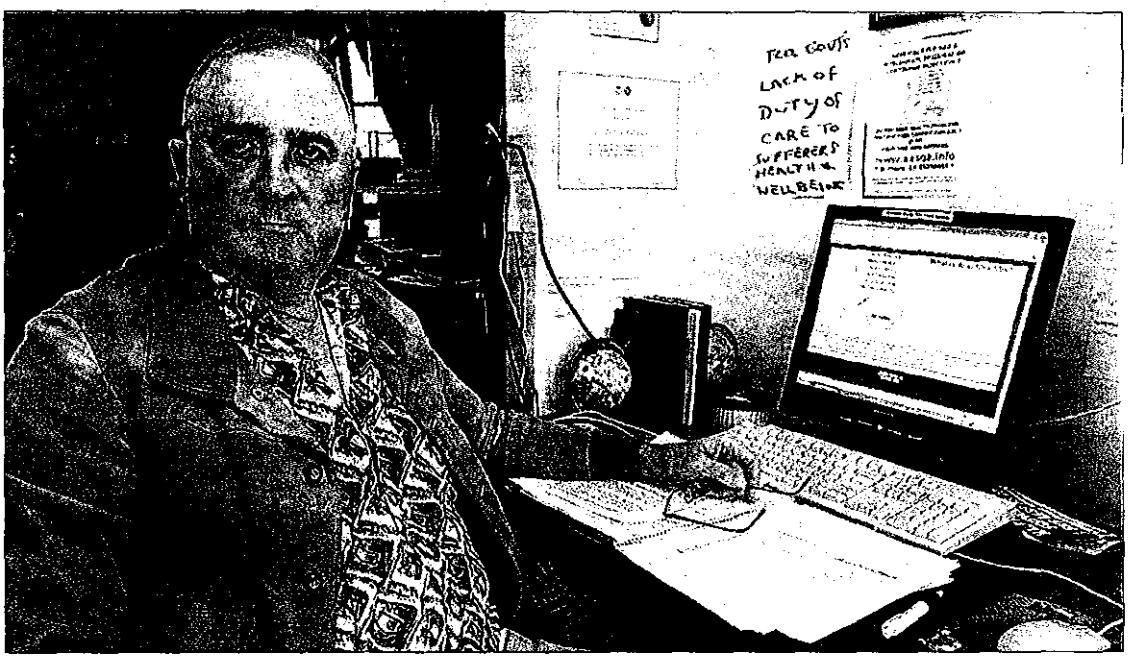
Call for inquiry into lethal procedure

By SALLY POEHLAND

A GOLD Coast support group for people experiencing the progressive neurological disease adhesive arachnoiditis is one step closer to its goal of gaining compensation for sufferers and reforms to medical practices.

President of the Australian Arachnoiditis Sufferers Queensland Association (AASQA), Peter Groves, said the group had sent a letter to the State Health Minister (Gordon Nuttall) requesting the Morris Inquiry into Queensland Health include an investigation into the use of Myodil/Pantopaque oil-based water contrast dyes, which can have long term horrendous side effects.

The dye enabled doctors to see the spine more clearly in a type of X-ray called a myelogram, used between 1945 and 1988.



DEMAND FOR INQUIRY ... president of the Australian Arachnoiditis Sufferers Queensland Association, Peter Groves.

"We sent a letter to the Health Minister on April 25, to be included in the terms of reference for the inquiry in regards to arachnoiditis," explained Mr Groves.

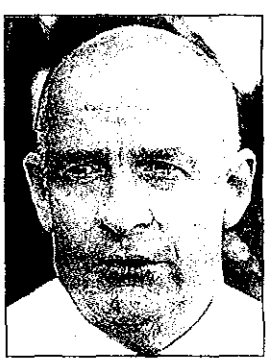
"We received a letter dated May 18, with instructions to contact the inquiry to include arachnoiditis in the terms of reference.

"We now await the reply to that request," he said.

Mr Groves said he had also received figures from Centrelink confirming that there were now more than 350,000 victims of the blue dye in Australia.

Victims of the dye's effects can suffer burning back pain, shooting pains in limbs, deep muscle pains in the back and limbs, spasms and twitches, burning feet, joint pains, numbness and tingling sensations, seizures and paralysis, visual impairment and feelings that insects are crawling on their skin.

"The disease is caused by the inflammation and fusion of the nerves and membranes of the spinal cord. The condition can take up to 20 years to develop," said Mr Groves.



State Health Minister Gordon Nuttall

Mr Groves' back problems arose in 1973 when he fell from a ladder while he was working as part of the VIP aircraft cabin crew in the RAAF.

Just four years after Mr Groves underwent back surgery, he began experiencing adhesive arachnoiditis symptoms, but it wasn't until 2002 he found out it was associated with the injection of dye.

"It causes a slow and painful death and there is no cure," said Mr Groves.

AASQA started on the Gold Coast in 2003 and has 80 members. The support group meets every second Wednesday of each month at the Currumbin RSL.

"Our aim is to further our cause to explain and bring to the public's attention this disastrous medical procedure that has maimed and destroyed the lives of what is now known as the silent epidemic," said Mr Groves.

"What we have here is a public health issue. A public awareness campaign should be mandatory and scepticism of obvious abnormalities is inappropriate, yet some doctors display this attitude. We are demanding the Federal Government set up a Royal Commission of inquiry to question the medical profession and their approach to medical ethics and medical procedures. For too long they have been above the law. They do not know what to do with us, that is the bottom line."

For more details contact 5535 6655 or visit www.aasqa.info.

"Our aim is to explain and bring to the public's attention this disastrous medical procedure that has maimed and

Gold Coast Sun

Australia's largest regional suburban Newspaper

Wednesday, June 22, 2005

Peter's medical mission

By NADINE FISHER

IT may seem like a mission impossible but Palm Beach resident and adhesive arachnoiditis sufferer Peter Groves intends to fight all the way to the courts to have the dye that causes the condition banned.

Mr Groves is the coordinator of the Arachnoiditis Association of Sufferers Queensland Australia (AASQA) and together the sufferers will launch a class action against the manufacturers that produce the dye which is used in medical procedures including: myelograms, epijurals and anaesthetics.

Mr Groves said the AASQA had recently set up a new website and in six weeks they had received 471 hits.

"One of these hits was from a US Government Department which turned out to be a Dean at Harvard University," he said.

"We are now in the process of getting a senate inquiry going because there are around 80 different side effects from this dye and 10 per cent of people die from it," he said.

"It can take up to 20 years for the side effects to start up and this situation has been covered up for 42 years."

Mr Groves said the dye was commonly used for back injuries in a procedure called a myelogram. "The oil in the dye does not dissolve but pools at the base of the spine and in the arachnoid spaces of the spine where it melts the nerves," he said.

"The ingredients of this dye include: iodine, benzine (petrol), hydrochloric acid, sulphuric acid and sodium permagnate, which melts holes in rubber."

Mr Groves said some of the symptoms of Adhesive Arachnoiditis were: chronic fatigue syndrome, multiple sclerosis, cancer, meningitis, blindness, joint pain, bladder and bowel problems, burning feet, unexplained heart attacks and many people were put on morphine for the pain. "This is the biggest scandal of the 20th century, other countries have banned its use - in Sweden it was banned in 1938," he said.

"Everyone, the doctors, drug companies etc, knew the side effects of this procedure and yet we are getting no help from government ministers to call for the senate inquiry."

"We want the government to stop doctors and drug companies from using this stuff and start a public information program to force doctors to be upfront with patients about procedures and medical substances used and their side effects."

Mr Groves said the Red Cross also needed to be screening blood for this condition as it could be passed on unknowingly.

"It can also be passed on to sufferers' children and we want these drug companies held accountable like in the United States," he said.

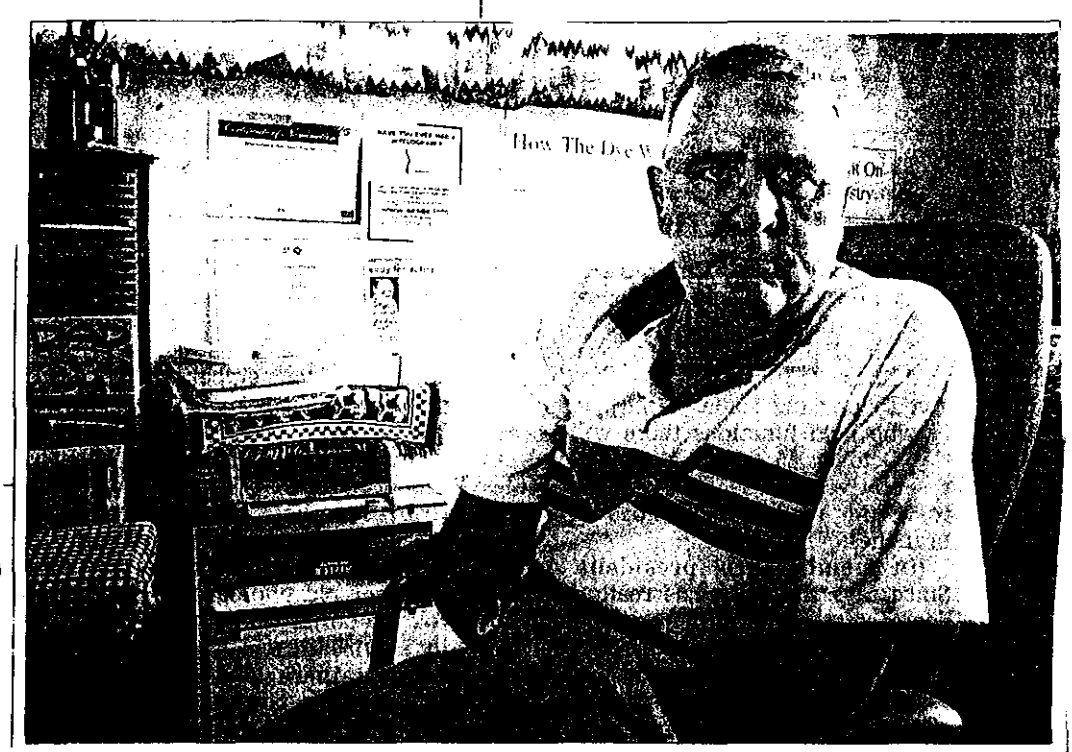
"Many sufferers are forced on to invalid pensions when it is the drug companies who should be held accountable."

"Doctors are running scared and many sufferers are having trouble getting a doctor to diagnose them as having it, but it's not them we're after, we're after the drug companies."

Mr Groves said the AASQA was four times the size of the MS Association and their website now had links to the US and UK Arachnoiditis sufferers groups.

"Our association meets on the second Wednesday of the month at the Palm Beach Neighbourhood Centre. For more information check the website www.aasqa.info or contact Peter on 5535 6655.

GOLD COAST MAIL OCTOBER 2 2003.



❑ PALM Beach resident and adhesive arachnoiditis sufferer Peter Groves are planning a class action against the manufacturers that produce the dye which is used in medical procedures including: myelograms, epijurals and

Griffith
UNIVERSITY

School of Medicine
Certificate of Appreciation

awarded to

Peter Groves

of

Australian Arachnoiditis Sufferers Queensland Association

for participation in the

Health in the Community Component of the Medical Program 2007

Associate Professor Michele Groves
Deputy Head of School
Director of Medical Studies
School of Medicine

Dr Michael Yelland
Associate Professor of Primary Health Care
Coordinator – Doctor and Health in the Community
School of Medicine

ADHESIVE ARACHNOIDITIS

Written on behalf of COFWA by:

Dr. Sarah Smith (nee Andreae-Jones) MB BS

Patron: Circle Of Friends With Arachnoiditis

March 2001

INTRODUCTION:

Adhesive arachnoiditis is an incurable inflammatory condition affecting the middle (arachnoid) layer of the meninges (which are the membranes surrounding the spinal cord). This condition is thought to be rare, although the real scale of the problem remains yet unknown.

TERMINOLOGY:

Meninges: 3 membranes which encase the spinal cord and brain. The inner layer= pia mater; middle= arachnoid (has a web-like appearance); outer= dura (tough) mater.

Arachnoiditis: inflammation of the arachnoid layer of the meninges. Mild forms often do not cause significant symptoms and may thus go undetected.

Subarachnoid space: the potential 'space' between the arachnoid (middle) and pia (inner) meninges; it contains the cerebrospinal fluid (CSF) which flows around the brain and spinal cord, providing it with nutrients and oxygen.

Epidural fibrosis: (also: peridural/extradural) scar tissue outside the meninges (literally: outside the dura, the outer layer of the meninges).

Intrathecal: this term denotes a site inside the dura; i.e. inside the thecal sac, which is another term used to describe the 3 layers of the meninges.

Adhesive arachnoiditis: the most severe type of arachnoiditis, causing scar tissue to form, which compresses nerve roots and impairs their blood supply, leading the various symptoms as a result (see below). Scar tissue may impede the normal flow of CSF.

Note that often in cases of arachnoiditis, scans may reveal epidural fibrosis, and it may well be that the converse is also true, although this is not often acknowledged by medical personnel.

Important note: for the purposes of clarity and brevity, this article will refer to adhesive arachnoiditis as AA. This is the clinically significant form of the condition.

CAUSES:

The majority of AA cases arise iatrogenically, that is, are caused by medical intervention.
It is helpful to divide the causes into 3 main groups:

1. **Chemically induced AA (CIAA):**
   This arises when chemicals are introduced into or around the subarachnoid space.
   - **Myelogram:** oil-based (Pantopaque/Myodil) and water-based: Metrizamide, Dimer-X, Omnipaque, Amipaque. Procedure used as a diagnostic tool before availability of MRI scans, still in use occasionally. Oil-based dyes remain in the central nervous system as either a thin film or as encapsulated deposits, commonly in the lumbosacral region or in the base of the skull (basal cisterns).
   - **Epidural /intrathecal steroid injection:** therapeutic measure commonly used in both acute and chronic back pain cases, including prolapsed discs. Benefit is questionable and temporary (up to 2-3 months). Risk of arachnoiditis is controversial; evidence of toxicity of the preservatives in the preparation points to a need to reappraise the continued clinical use of this procedure. Preservative-free solutions (Celeston Soluspan/Decadron) may confer lower risk, but this invasive treatment remains one in which risk may well outweigh benefit.
   - **Epidural anaesthetics:** again, a controversial subject; use in healthy obstetric patients to minimise pain during labour may be unwise if there are suitable non-invasive alternatives; combined spinal/epidural procedures involve placement of the anaesthetic agent directly into the spinal fluid. Again, it is the preservatives which are likely to cause toxic damage to nerve roots, although

the anaesthetic agents themselves may also directly affect nerves. The practice of regional anaesthetic techniques such as epidurals in conjunction with a general anaesthetic (used in paediatric operations) is a cause for considerable concern as the patient is unconscious and cannot therefore alert the doctor performing the procedure to pain due to inadvertent injection directly into nerve roots. Note also that in procedures of epidural steroid injections, it is common practice to combine this with local anaesthetic to confer immediate relief (steroid aiming to provide a more sustained relief over weeks): thus conferring "double jeopardy".

- **Chymopapain:** this agent has been used as a chemonucleolytic agent; it is an enzyme, which breaks down disc material that has leaked due to a disc herniation (prolapse).
- **Intraspinal chemotherapy agents:** e.g. methotrexate which is used to treat certain cancer conditions and is deemed to provide higher available drug concentrations than if given intravenously; however some authors have suggested that it is unnecessary to use intraspinal injections.
- **Chemical meningitis:** may result from any of the above procedures; it involves acute inflammation of the meninges, often in both the spinal and cerebral (around the brain) areas.

2. **Mechanically-induced AA (MIAA):**
   - **Spinal surgery:** especially multiple surgeries.
   - **Trauma**
   - **Multiple lumbar punctures**
   - **Spinal stenosis** (when chronic)
   - **Anatomical abnormalities:** especially degenerative conditions: e.g osteophytes (bony protuberances)
   - **Chronic disc prolapse:** including leaked disc material, which is known to be highly irritant to nerves.
   - **Blood:** bleeding into the spinal fluid due to invasive procedures or trauma (as above). Blood is extremely irritant to nerves. Subarachnoid haemorrhage may occur spontaneously (no invasive procedure precedes it) and can cause arachnoiditis.
3. **Infection:**
   - **Meningitis:** viral/bacterial; inflammation in the meninges; usually cerebral, but may also affect the spinal meninges. Lumbar puncture is required to establish a diagnosis.
   - **Tuberculosis:** before the advent of widespread myelograms etc. TB was a major cause of spinal AA, often in the thoracic (chest) region of the spine. There has been some increase in the incidence of TB in Western countries in recent years, possibly due to immigration from India and Pakistan, where TB is still common. TB of the spine (Pott's disease) remains relatively uncommon though.

Note: observations of an anecdotal nature, arising from over 3 years of regular communication with AA sufferers around the world have led to the following observations:

1. CIAA tends to cause a more florid, severe condition with widespread symptoms; in the cases where multiple chemical insults have been sustained, there is a more severe picture, so that one can postulate that the severity of the condition is proportional to the number of invasive chemical procedures have been undergone.
2. MIAA tends to cause more localised damage, which affects one, or two nerve roots and causes symptoms related to this specific damage.
3. Commonly, patients with AA will have undergone a variety of medical procedures, the condition being multifactorial in origin. This gives rise to problems with regard to attempted litigation. Further investigation comparing CIAA and MIAA needs to be undertaken in order to discern a workable clinical picture, which may be useful both in diagnostic terms and within a legal framework.

SYMPTOMS:

AA does not have a typical clinical presentation, although there are a number of features, which are common in people with the condition. However, the picture is somewhat complicated by the fact that the symptoms of AA occur against a backdrop of the original spinal problem for which invasive procedures were undertaken (except in a small minority in which no spinal condition has occurred, for instance, in AA secondary to epidural anaesthesia in childbirth).

It is important also to remember that a number of the symptoms experienced are common to various chronic illnesses and may well arise secondary to the general debility occasioned by unrelieved pain and stress resulting from dealing with illness that is relentless for years on end.

Chronic pain is not regarded by most of the medical profession as detrimental of itself; however, recently some doctors are beginning to voice a different point of view, recognising that unrelieved pain constitutes a source of constant stress on the body, resulting in over-production of stress response chemicals in the body, such as adrenaline, insulin and cortisol. These substances cause a variety of problems. In America, highly sophisticated PET scans have shown that chronic pain in some way alters the way in which the brain responds to stress or pain; the concentration of neurotransmitters (chemical nerve messengers) in certain brain areas seems to vary from that of healthy people.

In 1999, a global postal survey of people with arachnoiditis showed the following results:

1. Pain (100%)
2. Numbness/tingling (86%)
3. Sleep disturbance (84%)
4. Weakness (82%)
5. Muscle cramps/twitches/spasms (81%)
6. Stiffness (79%)
7. Fatigue (76%)
8. Joint pains (72%)
9. Balance difficulties (70%)
10. Loss of mobility (68%)

Other common symptoms seen in the typical case:

1. Bladder/bowel/sexual dysfunction(68%)
2. Increased sweating (63%);
3. Difficulty thinking clearly/Depression (63% /62%);
4. Heat intolerance(58%);
5. Dry eyes/mouth(58%) and
6. Weight gain (50%).

Heartburn/indigestion is also a common problem; often this is related to use of NSAIDs (anti-inflammatory drugs). Difficulty in swallowing may be related to this or may arise (less commonly) due to inco-ordination of the gullet muscles.

Headaches are also a common feature. Many people seem to develop skin rashes, for unclear reasons. (some may be related to medication such as anticonvulsants).
Other less common problems experienced include: Tinnitus (ringing in the ears), dental problems (tooth decay may be worsened by dry mouth due to loss of the protective power of saliva), abnormalities in the menstrual cycle, eyesight problems (difficulty in focussing may be due to medication).

The pain tends to be intractable and resistant to treatment, being predominantly neurogenic in origin. This causes persistent burning pain and intermittent stabbing or electric shock type pains. Burning in the feet is common and may be accompanied by a sensation of walking on broken glass.

There may also be a component of central pain, which is well known to be difficult to treat. This involves various bizarre sensations, such as pain felt on light touch or a change in temperature (allodynia) or pain felt in a different part of the body to the one being touched. People also experience sensations such as water running down the leg, or insect bites.

One doctor has likened the pain of AA to that experienced in cancer, but without the relief of death. Indeed, some sufferers become suicidal due to the unrelenting pain and the neurological deficits they experience.

There are a range of systemic symptoms which constitute a debilitating condition that severely impairs the sufferers' quality of life.
AA is incurable and may be progressive in some cases. Usually people tend to 'plateau out' at a certain level of pain/loss of function, but in a minority, a relatively trivial event such as a slight fall or car accident, can set off a rapid decline.

Note: in the survey, a number of respondents had a diagnosis of an autoimmune disorder such as Lupus, Sjogren's, Rheumatoid arthritis. There appears to be a possible link between AA and autoimmune type

problems. Out of 317 survey respondents, 27 had thyroid disorders, all except one having previously undergone myelography. As myelogram dyes contain iodine, there may be a significant link between the myelogram and subsequent thyroid disease; this is currently being investigated. There are also a number of arachnoiditis patients who have also been diagnosed with Multiple Sclerosis, as well as several more who have undergone investigation for MS. Those who have a diagnosis of fibromyalgia in addition to arachnoiditis are probably suffering from the condition as a secondary feature of the underlying arachnoiditis; fibromyalgic type symptoms of diffuse muscle tenderness and fatigue are common in arachnoiditis patients.

Important note: not ALL symptoms can be ascribed to arachnoiditis. Any new or increasingly severe symptom which persists for more than 48 hours should be fully assessed at a medical consultation.

DIAGNOSIS:

Many people who have symptoms such as those described and a history of risk factors for AA still have difficulty in getting a diagnosis. As the condition is perceived to be rare, doctors often do not consider it a likely diagnosis. It is important that treatable conditions such as recurrent disc herniation are identified and treated and this can be achieved through the use of an MRI scan. High resolution scans may also be able to demonstrate AA, although in the early stages it might not be picked up. In any case, one must bear in mind that MRI scan results often fail to correspond accurately to the clinical picture. Heavy reliance on the need for a diagnosis is unadvisable, and often unnecessary, as management of symptoms is the only option, AA being incurable.

EMG (electromyogram) or NCV (nerve conduction velocity) tests may be performed to assess nerve damage. If there is loss of bladder control, urodynamic studies may be undertaken to fully assess the problem.

DIFFERENTIAL DIAGNOSIS:

This refers to other similar diagnoses which may be relevant:

- **Failed Back Surgery Syndrome:** in fact, arachnoiditis probably accounts for over 10% of FBSS cases; FBSS is common, incidence varying from 25% to 40% of all spinal surgery cases. The commonest causes include: epidural fibrosis, recurrent disc herniation, spinal stenosis (narrowing of the spinal canal or the foramina (holes in the vertebrae) through which the nerve roots exit from the spinal cord. It is important that treatable causes such as reherniation of a disc, are identified and treated:
- **Multiple Sclerosis:** as mentioned above, it is quite common for arachnoiditis patients to be investigated for MS.
- **CRPS:** previously termed RSD: reflex sympathetic dystrophy, CRPS Type I refers to problems in one limb, often after trauma/surgery: pain, swelling and changes in skin colour and temperature, abnormal sweating: increased/decreased (bone density lost in later stages). CRPS Type II (previously causalgia) refers to more widespread problems, other than in the area affected by an injured nerve and resembles arachnoiditis. Continuous pain, allodynia (pain from non-painful stimulus such as light touch/clothing/temperature change) and/or hyperalgesia (heightened pain) can occur. (also: skin rashes, abnormal body temperature, tremors (shakes), tripping/falling.)
- **Cauda Equina Syndrome:** acute CES is a surgical emergency; loss of bladder/bowel function, saddle anesthesia (loss of sensation or tingling in the buttocks and around the anus/vagina/genitals), leg weakness and severe pain in the lower back/limbs/genitals. CES is basically a descriptive term for a set of symptoms. It may arise when there is a severe compression in the cauda equina, (horse's tail) at the lower end of the spinal cord (acute causes include large disc prolapse). A chronic equivalent to CES may arise in arachnoiditis.

MANAGEMENT:

As explained above, AA is incurable, but there are a number of measures which may be helpful in managing symptoms.
Sadly, in a survey in 2000, I found that quite a high proportion of AA patients continue to experience very troublesome levels of pain as well as other symptoms including loss of function.

In part, this may be due to reluctance of medical personnel to prescribe medication in the long term, especially narcotic painkillers, which are perceived as carrying a high risk of addiction. In fact, narcotics used for pain relief (in comparison with recreational use) carry a very low risk of addiction in the generally accepted sense of the term. Whilst the body becomes accustomed to a certain level of medication and goes into withdrawal if the drug is abruptly discontinued, psychological dependence is uncommon. Behavior that may be regarded by medical and paramedical practitioners as addictive, may arise out of a desperate bid to find

adequate pain relief. Often, doctors are willing to prescribe medication such as anxiolytics or hypnotics (treating anxiety or insomnia) such as Valium (diazepam) or related drugs: which are in fact, far more addictive than narcotics (morphine and related drugs) and carry a risk of tolerance (needing increasing doses) that far exceeds that of narcotics. Usually, what the patient really requires is an increased dose of painkiller to relieve their 'anxiety' or sleep disturbance. Families may also be wary of narcotic use, deeming it as inappropriate; the stigma is still very much in evidence.

Management of AA should revolve around a wholistic approach and may require a multidisciplinary team involvement. However, this should be overseen by one individual amongst the medical personnel (usually the primary doctor or GP) It is vital that the patient develops a working therapeutic alliance with his/her doctor(s). This will pave the way to a good level of compliance and a mutual trust and respect.

Treatments should be implemented one at a time and must be trialled for at least 4-6 weeks (unless there are severe side effects or allergic response) in order for adequate assessment of their efficacy can be made.

Round- the- clock dosing is essential to achieve effective pain relief and minimize side effects and tolerance (need for increasing doses to achieve the same effect).
Usually side-effects begin to subside after about 10-14 days of continued usage, so patients should be advised to ride out the first few days of sedation, nausea etc. if possible. Persistent side effects such as constipation and dry mouth are common, but may be managed fairly easily.

Below is a brief outline of the various strategies which comprise a multimodal programme:

1. **Medication:** often oral, but may also be via a patch. Typically, a triad of narcotic/antidepressant/anticonvulsant is used, +/- muscle relaxant +/- anti-inflammatory. (see below for more detailed list)
2. **Physical therapies** : massage (Shiatsu), chiropractic, cranialsacral therapy, Myofascial Release techniques; stimulating: Low Level Laser Therapy, Ultrasound, TENS; Acupuncture;
3. **Exercise:** loss of mobility may have a knock-on effect in general debility, and can directly contribute to development of osteoporosis; gentle exercise is helpful; 'No pain, No Gain' does NOT apply and exercise regime needs to be carefully tailored to the needs of the individual. Feldenkrais, hydrotherapy, isometric exercises are often helpful.
4. **Treatment of specific problems:** e.g bladder dysfunction; poor circulation in extremities
5. **Management of side effects:** such as constipation
6. **Nutritional:** avoidance of caffeine and possibly trigger foods; supplements such as vitamins, MSM, glucosamine.
7. **Herbal/homoeopathic:** NB. Herbal preparations may interact with prescription medication; St. John's Wort (dépression); Gingko
8. **Lifestyle measures:** smoking: preferably should be stopped as it worsens circulation; alcohol: may interact with medication; if taken in excess, as a strategy to aid sleep/reduce pain or distress, it may act as a depressant i.e. causing a low mood. Illicit drugs such as cannabis have been reported as helpful in reducing muscle spasms and enhancing pain relief; cannabis is currently being trialled in the UK for use in MS patients.
9. **Psychological:** often people with arachnoiditis are reluctant to admit to emotional distress because they have been labeled as having a psychosomatic illness in the past; however, psychological difficulties are only to be expected in a debilitating, incurable illness. Often complex psychological situations may arise, particularly with regard to the causative factors (being mostly iatrogenic): anger and bitterness can be very strong and persistent, often being fuelled by day-to-day frustrations over loss of function, relationship troubles (as with any chronic illness, considerable strain is put upon partners and family) and fear for the future. Individual counseling, couples, or group therapy may help address issues on grief (over loss of health, role, financial security, self-esteem etc.etc.) In addition, patients can be instructed on strategies for self-help in learning to cope with ongoing illness and pain; these include Cognitive Behavior Therapy, which can be very helpful
10. **Support groups:** groups are invaluable in allowing sufferers to be in direct contact with others who are going through the same sort of troubles. This contact helps to reduce the strong sense of isolation which is extremely prevalent in people with chronic illness.
11. **Information:** the Internet can be a very useful resource, but it must be remembered that not all the information is from reliable sources; one should always check that material uses reputable (and verifiable) references. Support groups can be sources of useful information on the condition and other issues regarding the day-to-day effects of the illness on various aspects of life.
12. **Aids:** ranging from simple measures such as pads to place in shoes to make walking more comfortable to

wheelchairs; these can really help in daily life.

Medication:

The majority of sufferers need to use a variety of medication in an attempt to reduce the pain.
The survey results showed the following as regards treatment regimes and in most cases, polypharmacy(a cocktail of drugs) is necessary:

- OPIATES (e.g. Morphine, Pethidine (Demerol), Methadone, Tramadol etc.): 171=54% (note: Buprenorphine: Temgesic is a partial opiate agonist: and partial antagonist; this means that it may give rise to withdrawal symptoms in patients who have previously taken strong opiate drugs)
- ANTI-INFLAMMATORY (e.g. Brufen, Mobic, Naproxen, Vioxx etc.): 144=45%
- ANTIDEPRESSANT (commonest amitriptyline; also Prozac etc): 90=28%
- ANTICONVULSANT (e.g. Tegretol; Neurontin; Vigabatrin): 84=26%
- MUSCLE RELAXANT: (e.g. Baclofen; Robaxin; Dantrolene; Zanaflex): 34=11%
- BENZODIAZEPINE (e.g. Diazepam, Clonazepam, Nitrazepam, etc.): 39=12%
- DIURETICS (for fluid retention): 17=5%
- INA (intraspinal narcotic agents= "the pump"): 8=2% incl. CLONIDINE: 2
- SCS (spinal cord stimulator): 2
- STEROIDS: 4 (1 via portal implant)
- QUININE (for muscle cramps): 3
- OXYBUTININ (for bladder muscle instability): 1
- BETHANECOL (for urinary retention): 1
- ETIDRONATE (for prevention of bone loss in osteoporosis): 1
- NONE: 10=3% PARACETAMOL/ASPIRIN ONLY: 4
- TENS: 2

Note low percentage on no medication or simple analgesia; generally, for respondents who were not on medication, this was due to inability to tolerate stronger medication due to side-effects or adverse reactions.

Most cases in the survey involved polypharmacy, with a combination of opiates with antidepressant and/or anticonvulsant being common. Anti-inflammatory medication (NSAIDs) usage was common despite a considerable number of respondents stating that they had had to discontinue use due to adverse gastric effects (e.g. gastric/duodenal ulcer, heartburn, gastric bleed), which are well known with this type of medication.

Antidepressant medication is used at a sub-therapeutic dose as regards treating depression (i.e. say 25mg amitriptyline rather than 75-150mg) it is useful for neurogenic pain. Tricyclic antidepressants are most effective, whereas SSRIs (newer type) such as Prozac are often poorly effective. Of course, in some cases, full antidepressant dose may be given to combat any depressive features compounding the physical problems. Anticonvulsant medication is useful for neurogenic pain.

Benzodiazepines: a group of drugs including valium: used either as a muscle relaxant or to combat anxiety, or perhaps as sleeping tablets.
Naturally, high doses of these drugs may cause significant adverse effects such as sedation, cognitive impairment, nausea and vomiting, fluid retention etc.

PROGNOSIS:

The outlook for patients with arachnoiditis is unfortunately as yet unknown. There has only really been one medical article written about this, published in the late 80s by Guyer. He contends that on average, life expectancy may be shortened by as much as 12 years. Arachnoiditis, as discussed above, is as yet incurable.

There is considerable controversy over whether it is a progressive condition. In the majority of patients, there may be a gradual decline over a period of years with increasing pain levels and some loss of function. Some people seem to reach a plateau and remain stable. Those who can stay off strong medication and are able to maintain a reasonably active lifestyle seem to do best. In a small minority, a quite minor injury from a fall or car accident can trigger rapid decline.

A few patients go on to develop complications such as arachnoid cysts (encapsulated fluid collections around the spine or in the brain), syringomyelia (fluid-filled cavity in the spinal cord) or hydrocephalus (enlarged ventricles in the brain). Other complicating conditions include: depression, osteoporosis (due to lack of mobility).
By and large, though, there are AA patients who have had the condition for up to 20 years and are still able to be relatively independent and reasonably mobile.
AA is not directly fatal. However, there have been cases of suicide due to the despair of unrelieved pain.

THE FUTURE:

One of the most tragic losses experienced by arachnoiditis patients is hope for the future. Most see a bleak and pain-filled existence centred around an unrelenting illness. However, we must never lose sight of hope: as Bernie Siegel wrote:

" Hope isn't statistical, and individuals recover. There will always be a first person to recover from every disease.....there is no false hope. False hope tends to be a recital of statistics, and people are not statistics. But there is false no hope."

What better note to end on than to quote Dr. Goodling, from Duke University, who said:

"It's so important for people who are hurting to know that the story hasn't been finished. Things are terrible now, but there's more to the story."

Rocco et al (xxviii) in a study of pressure gradients in the epidural space, concluded that as resistance to inflow of fluid was significantly higher in the diseased epidural space, "spread of anesthetics might be difficult to predict".

In 1955, Hurst conducted studies on monkeys (xxix), which demonstrated that a wide range of chemicals, when introduced into the CSF, produced an immediate pathological

response, which "proceeds steadily to its termination". The early stages are asymptomatic, but after a latent period, the clinical picture is then one of "severe and progressive signs and symptoms". This is similar to the picture in arachnoiditis, and therefore all short-term studies (which make up the majority of the evidence concerning safety of ESI) will fail to address the issue of arachnoiditis, which tends to occur after an indeterminate interval following exposure. Chymopapain, an enzyme that has been used for chemonucleosis in treatment of prolapsed discs, also has been implicated in causing epidural fibrosis (xxx) and animal Studies show severe nerve damage if injected into the nerve sheath (xxxi). In fact, one paper suggests use of intrathecal chymopapain for use as a model for chemically induced spinal cord injury. (xxxii)

PRESERVATIVES IN SPINAL INJECTIONS In 1975, Kelly et al (xxxiii) wrote a paper describing the neuropathological effects of intrathecal water. They concluded that infusion of distilled water intrathecally could cause distinctive lesions of spinal roots and cord. It follows therefore, that if a substance as inert as water can cause damage, that more complex preparations are likely to carry some risk also. As early as 1954, Moore (xxxiv) advised that local anaesthetic administered epidurally should be free of preservatives. Malinovsky (xxxv) suggests that "neurotoxicity can result from decrease in neuronal blood supply, elicited by high concentrations of the solutions, long duration exposure to local anaesthetics, and the use of adjuvants." Some authors suggest that arachnoiditis occurs as a result of the vasoconstrictive component of the anaesthetic, whilst others say that contaminants (xxxvi) or preservative agents are responsible. It must be stressed that ANY drug preparation injected in to the spine, may contain preservatives such as benzyl alcohol, polyethylene glycol, and chlorobutanol (a derivative of chloroform) and that these carry a risk of neurotoxic effects. Another preservative that can cause reaction is sodium bisulfate, which may trigger a severe allergic reaction if the patient is susceptible (and it is unclear how many of the general population may be susceptible). Burm (xxxvii) states that epidural anaesthesia results from the interactions of local anaesthetics with nerve structure within the subarachnoid space, which they reach by uptake into the epidural fat and via systemic absorption, and that consequently, epidural doses need to be much higher than spinal doses. Bearing this in mind, it is unsurprising that there is evidence that epidural anaesthetic agents such as those used in childbirth also carry a risk of neurological damage.

It is vital that patients be FULLY informed of the risks for these procedures outlined above, so that they can give an **informed consent**. Unfortunately, it is commonplace for this not to be the case. Many doctors feel that it would be confusing to the patient to be given a detailed breakdown of the relative risk of each adverse effect. In addition, arachnoiditis continues to be viewed by the medical profession as a RARE complication and as such, does not warrant mentioning. As regards therapeutic techniques, it is essential that the potential benefit be weighed against the risk of the procedure causing serious adverse effects. Regrettably there is an under-reporting of adverse effects, so that clinicians may not have access to accurate information to pass on to the patient.

PROGNOSIS

Arachnoiditis has been described as an insidious disease that is incurable. Guyer's paper on the prognosis of arachnoiditis (xxxviii) suggests that there tends to be a spectrum of the course of the

AUSTRALIAN
ARACHNOIDITIS
SUFFERERS
QUEENSLAND
ASSOCIATION Inc.®
Registration No: IA 32655

AASQA PRESIDENT
Ph: 07 55356655
Mobile: 0428 356 655
Email: peter.groves@aasqa.org
Mail: The Secretary
PO. Box 1118
Palm Beach
Queensland Australia 4221

MAY NEWSLETTER NO 3 FOR2008

Hi members, well its that time of year for the AGM, I have enclosed the nomination form to be returned by the 29th of May as you can see we are operating on a skeleton staff. We would like to say at full staff but I get the impression there are forces at work to see us fail, however, we will keep going due the very good donations from sufferers that have faith in the current operation, and we are grateful for that.

I have been very attending forums through the Volunteering Gold Coast,a 20/20 Gold Coast summit was held on April 02, where I was able to sit in on the group with Senator Joe Ludwig Minister for Human Services assisting the Minister for Health.

I have enclosed the submission in which was for the 20/20 Canberra summit id no 6785, No 5 Long term Health Strategy.You can go to the 20/20 website/submissions.

I also managed to get into the local paper, my story you can find a copy enclosed.

AASQA is also found at QFINDER, we have been selected for listing in the directory,to look up go www.health.qld.gov.au/qfinder I believe this to be historical, now that Arachnoiditis is getting official recognition and the hard work is finally getting acknowledged.

The office of State Revenue, has approved AASQA as an Exempt Institution which (a)has as principle object or pursuit- (i) fulfilling a charitable object; or promotion of the public good.

For those interested and could seek counseling, I spent 10 weeks last year at the Bond University psychology, talking to an intern she was very supportive and the final report went to great detail which was found to be exhaustive, but I was able to give future students very important information to pass on about Arachnoiditis.

I don't have a current G.P., in the past year I have seen (4) and did not wish to talk about it. My high sugar levels were of concern actually they were obsessed about it, I now have them down to (10)so no medication or insulin for me. It can be managed by diet/exercise.

Information has come across this desk that as far back as the Hawke Government that Arachnoiditis was an issue and was refused a hearing, and when Beazley was opposition Leader, stitched up a deal with the Howard Government, what a bunch of evil people.We have become a burden to society, forced onto disability pensions, others have business being bankrupted, having to pay high specialist fees, I can assure you the politicians are becoming very aware of this, also losing their homes, all because the medical profession can have a second holiday home or the second Mercedes. I am asking you sufferers to be consistent and keep contacting your local state/federal members of parliament. To pursue them towards a **"ROYAL COMMISSION OF INQUIRY", INTO THE USE AND ABUSE OF MYODIL/PANTOPAQUE.**

To finish of please do not forget to send in your nomination form, in by May 29th.

Your editor,
Peter J Groves.
President.

Topic Area: Health

To search for a submission within the topic either a Name or Submission ID, if known, and select Search.

Publication Name: Submission ID:

Submission 6785 : Australian Arachnoiditis Sufferers Queensland Association Inc

5. A long-term national health strategy

"Arachnoiditis:Tragedy of a Toxic Chemical" Adhesive Arachnoiditis represents the most severe form of inflammatory disease process involving the pia-arachnoid membranes of the brain and spinal canal.It is produced by an inflammatory reaction to the presence of foreign body substances in the subarachnoid space. These can be natural such as bacterial or blood or iatrogenic such as iophendylate or water soluble substances being used for the purpose of diagnostic myelography. AASQA demands Royal Commission of inquiry into the abuse and use of the oil based contrast (dye) Myodil, and also demands a medical research institute /Registry also a compensation Foundation for the pain and sufferering.Iophendylate:is a formula put together by Glaxo-Smith Kline/ Eastman Kodak consists of "Radioactive Iodine,Benzine, Sulphuric acid,Potassuim Permanganate,Hydrocloric Acid,Acetone (battery acid) the cork plugs laced with asbestos to protect the corks, these toxic chemicals would burn hole in wooden cuboards,styrofoam and rubber floors. From 1948, Glaxo was aware that that the product was not stable,,Glaxo kept a product on the market which its own Standards Committee was recommending should not be marketed.DrSara Smith(nee Andrea - Jones)MB BS: from the UK`S national organisation for healthy backs.A 37 page history of adverse findings (13 pages of reference footnots from 1938-2000 against pantopaque. How it caused Arachnoidits and evidence of neurotoxicity,cysts,associated syrinx resulting in progressive spastic paraparesis, chronic focal seizure, encephalopathy causing post-operative convulsions,blindness,granulomatous mengitis in the brain and spinal cord ect.Her 2002 article:"HOW THE DYE WAS CAST:SHEDDING LIGHT ON A DARK INDUSTRY" Myodil ,the contrast the Government insists was ceased to be used in 1987, as recent as 2003, was being used in Papua New Guinea on Babys`from 3 years old supported by Australian Aid Abroad(Ausaid) Department from Paediactrics Medical Manual.The New Zealand Ministry of Health completed its report 2002 (a world first)on Arachnoidits states; that we have the "SWORD OF DAMOCLES HANGING OVER OUR HEADS".children with leukemia following chemotherapy going into remission would have the burden of suffering Arachnoditis for the rest of their life. From 1947 to 1980`s 1 million myelograms were performed each year with Myodil/Pantopaque. Based on centerlinks figure 1997 there were approximatley 350,000.00 sufferers of the blue dye,Minister this a pandemic this suffering must be stopped.There was no informed consent, which means constitues major fraud, this human rights abuse ,The TGA IS NEGLIGENT "MISINFORMATION,BLATANT DECEPTION IN PART A MAJOR CONSPIRACY WITH DRUG COMPANYS TO CAUSE INTRACTABLE PAIN ON VICTIMS INCAPACITATED BY INCURABLE NEUROLOGICAL DISEASE WITH DEBILITATING LOSS OF BODILY FUNCTION.The dyes have made we sufferers a burden to society, AASQA DEMANDS THAT Glaxo-Smith Kline and others be made accountable we demand Justice for those who have been forced onto pensions, suiciding,as the progressing iatrogenic disease has claimed many into paraplegia,quadriplegia have lost their homes having to pay large medical bills and being bankrupted.

Reproduced here is the paper, which introduces Iophendylate (Pantopaque/Myodil), to the British medical establishment. The chemical processes described are unclear on the photocopy in my possession; however, these are not what interest us. I have marked those passages, which do have a bearing on our situation in bold type. This paper goes a long way to explaining why our doctors thought that this chemical was safe at the time of its' introduction. It should also be noted that this paper was published at the height of WWII, if there were doubts about it, investigation would be a subject best left on the "back burner" until peace re-established itself in the post-war, US dominated, world. (MF)

Soc.Chem.Ind 63-223(1944)
THE PREPARATION OF IODINE-CONTAINING X-RAY CONTRAST SUBSTANCES. IV. ETHYL IODOPHENYLUNDECOATE (PANTOPAQUE)
Authors: Wilson Baker, E.E.Cook, and (in part) W.G.Leeds

A detailed process is described for the preparation of ethyl-iodophenyundecoate (I), an x-ray contrast substance for the visualisation of the spinal canal and other bodily cavities. Undecenoic acid and benzene are condensed to give phenylundecoic acid, which is directly iodinated in acetic acid solution in presence of iodic acid and the product enterified(sic). The overall yield of purified material is 70%.

Until recently the only compounds available for the X-ray visualisation of the spinal canal have been iodised vegetable oils, in particular iodised poppy-seed oil which contains about 40% of iodine. These iodised oils are of variable quality and are unsatisfactory in clinical practice.

Owing to the reactive nature of the iodine atoms which are in aliphatic combination, samples are often unusable owing to free iodine, or they may slowly decompose in the body with liberation of iodine, causing toxic symptoms particularly in contact with diseased or inflamed tissues.

This instability is especially objectionable in the spinal canal, where that portion of the oil which cannot be withdrawn, may be finally absorbed only after a period of years. For this reason there is considerable reluctance to use iodised poppy-seed in myelography.

A clinically satisfactory, non-toxic oil containing chemically inert aromatic iodine has been described by Strain, Plati and Warren.

This is ethyl p-iodophenylundecoate (I)1 C4H4I(CH2)I10CO2Et, a product which has been prepared by the Eastman Kodak Company under the name of "Pantopaque", but it is not yet generally available. It has the advantages over iodised poppy-seed oil of being more fluid and more rapidly absorbed without toxic symptoms after intrathecal injection. The iodine content is about 30%, so that it is rather less radio-opaque than iodised poppy-seed oil.

The ethyl iodophenylundecoate was prepared by the American workers by the condensation of iodobenzene with ethyl undecenoate in presence of aluminium chloride, and is probably a mixture consisting mainly of (I) with a smaller quantity of p-C8H4I CHMe (CH2)10CO2Et, and doubtless traces of the ortho-isomeride. The yield claimed is 40%.

Some of the ethyl iodophenylundecoate was prepared by the method of Strain, Plati and Warren, and, although clinically satisfactory, the yield was only 10%, and no higher yield could be obtained either under the original or modified conditions, or by the use of other condensing agents or solvents.

It became clear that a considerably improved method for preparing ethyl iodophenylundecoate would have to be found if it was to be produced technically on the large scale, and amongst the methods investigated since 1942, in this laboratory only the direct iodination of phenylundecoic acid or ester showed promise.

Close study of the reaction led ultimately to the process now described, by which clinically usable ethyl iodophenylundecoate is prepared in 88% yield from phenylundecoic acid, or 70% overall yield from undecenoic acid and benzene.

After the present process had been worked out a second paper by Plati, Strain and Warren (Ibid 1943, 65,1273) described the direct iodination of simpler phenyl-fatty acids using sodium nitrite as oxidising agent, but the yields were not good (14-50%). It seems clear that the experiments were initiated because "a method for the direct iodination of phenyl-fatty acids was essential" in order to avoid the poor yield in the condensation of iodobenzene with unsaturated esters.

In the present process phenylundecoic acid is prepared by the condensation of benzene with undecenoic acid in presence of aluminium chloride. This product is probably the a-phenyl derivative, but it may contain the isomeride with the grouping CHPhMe.

The phenylundecoic acid is then iodinated in acetic acid solution in presence of iodic acid and a little water. Under these conditions the iodine substitutes almost wholly into the nucleus, undoubtedly mainly in the p-position, but a very small amount of iodine appears to enter the side-chain in the a-positive to the carboxyl group.

It is considered essential that this aliphatic iodine should be removed if the final material is to be completely stable in the body. The crude iodinated acid is, therefore, first refluxed with aqueous alcoholic sodium hydroxide, and then oxidised with excess of potassium permanganate in acetone, thus degrading any unsaturated or hydroxy-acids to homologues with one or two fewer carbon atoms, so that the iodinated acid as isolated contains small

quantities of iodophenyldecoic and iodophenylononoic acids. Finally the saturated iodinated acids are esterified with alcohol and sulphuric acid and the esters distilled.

The fact that the final product is not entirely homogeneous is no disadvantage in X-ray diagnosis. The material prepared as described here has been tested in myelography by Professor H.W.B.Cairns, F.R.S and doctor F.H.Kemp at the Radcliffe Infirmary, Oxford and found to be completely satisfactory.

In bulk it possesses a pale yellow colour which is difficult to remove, but in analysis and physical properties it is otherwise extremely similar to "Pantopaque".

Both products may be sterilised in scaled tubes at 100 degrees without alteration, but should be stored in the dark as they develop a light brown colour when exposed to sunlight.

The iodination of phenylundecoic acid in presence of persulphates, in particular potassium persulphate, has also been investigated. In these cases only about half the iodine enters the nucleus, and it is possible to introduce two atoms of iodine into the molecule, and then to remove the aliphatic iodine by hydrolysis and oxidation. Although the material thus prepared is satisfactory the yield is only about 30% from phenylundecoic acid.

Experimental

Phenylundecoic acid (cf. Fourneau and Baranger): Powdered aluminium chloride (310g;1.5mols. optimum quantity) is added to anhydrous benzene (1200cc; purified by concentrated sulphuric acid) in a 3litre flask fitted with a dropping funnel and mercury-scaled stirrer and cooled in an ice-salt mixture.

During 45 minutes a solution of undecenoic acid (284g;1mol.)in benzene (200cc) is run into a well-stirred mixture, the temperature being kept between 5 and 10 degrees. The mixture is then warmed slowly to 10 degrees (sic), stirred for a further half-hour, poured into crushed ice (800g) and concentrated hydrochloric acid (500cc) with stirring and the benzene layer separated.

The aqueous layer is extracted twice with a little benzene and the united extracts are shaken with dilute hydrochloric acid, then water, dried over calcium chloride, and distilled, yielding phenylundecoic acid (318g;78%), h.p. 210-235/21 mm.

Iodination of phenylundecoic acid.

In this process all-glass apparatus must be used **or corks protected by asbestos**. A 3 litre flask is fitted with a 2 foot length of glass tubing 1 inch in (diameter) cooled externally by a 1 inch spiral of thin **lead piping** through (which) cold water is passed.

The flask contains phenylundecoic acid (200g;1mol) (sic) (150g;1.5atoms(sic)), a solution of iodic acid (60g) in water (sic) glacial acetic acid (1litre) and is heated on a sand-bath (sic) deposition of iodine in the condenser refluxing must be gentle (about 3 hours and then vigorous for a further 13 hours. The (?) acid and excess of iodine are now removed under reduced pr(?) a water-bath, the residue in the flask is diluted with (?) (1litre) and extracted several times with benzene. The (?) extract is freed from iodine by shaking with a saturated solution of sodium bisulphite, then with water, dried over calcium (?) chloride and the benzene removed by distillation.

Removal of aliphatic iodine.

To a solution of the iodinated (?) alcohol (1litre) is added sodium hydroxide (150g) in water (?quantity) the homogeneous mixture heated on the water-bath for (? time) and then most of the alcohol removed under diminished (?). The product is diluted with water, acidified with hydrochloric acid(?) and extracted with benzene. The extract is washed with (?) and dried over calcium chloride, the benzene removed under di(?) pressure, and the residue dissolved in alcohol free acetone (?) in a 3 litre flask fitted with a mercury-sealed stirrer and c(?). Powdered potassium permanganate (10 or 40 g.(?)) is added and the mixture(?) stirred and refluxed on a water bath for 1 hour when excess(?) permanganate(?) is still present. The acetone is removed by distillation(?), water added, and sulphur dioxide passed to remove mercuric(?) dioxide and liberate the iodinated acid as the upper layer(?) of(?) the(?) mixture is well extracted with benzene, the extracts are washed(?) and (?) the benzene and traces of water removed by distillation (?) under (?) reduced pressure from a water-bath.

Esterification of iodophenylundecoic acid.

The iodophenylundecoic acid is refluxed with alcohol (500cc) and concentrated sulphuric(?) acid (50cc) for 16 hours, the alcohol removed under reduced(?) pressure(?), and the product poured into water and extracted thoroughly(?) using(?) ether. The combined extracts are washed with saturated _____(?) bisulphate solution, then aqueous sodium bicarbonate, and distilled(?) water. After drying over anhydrous sodium sulphate the e____ (?) is(?) shaken with charcoal which removes most of the colour, the(?) _____(?) removed , and the product distilled from an air.bath. _____(?) fraction of b.p. up to 190degrees/0.8mm, was discarded and the fraction(?) of(?) b.p. 190-210 degrees/0.8mm (280g) was collected. The b.p. is(?) _____(?) mainly 218-220degrees/0.5mm, by distillation over a free(?) _____(?). Found: C 55.6,55.7: H 7.6,7.6: I 30.2, 31.2%: n(?) _____ (?) d 25 over 25(?) 1.2560. Calc(?) for
C19H2902I 30.5%.

C and H values may indicate the presence of some iodinated _____(?) carbon: the iodine values vary owning to the difficulty with(?) _____(?) when(?) these compounds are oxidised.

The pale yellow colour of the product may be further reduced(?) by(?) dissolving in dry light petroleum (600cc;b.p.40-60 degrees(?)). Then(?) filtered(?) for half an hour with charcoal and the filtrate shaken with Merc(?) (?)mann alumina(?), filtered, and the solvent removed under di(?) pressure in the water bath.

The Dyson Perrins Laboratory
Oxford University
Received **May(?) 1944**

Flare Ups

Tuesday, 03 May 2005

Pretty much every arachnoiditis sufferer will have experienced a 'flare up' at some time or another.

Whilst the majority of us tend to 'plateau out' over time, i.e. become more or less stable, with only gradual or no decline, there is often some degree of fluctuation of symptoms within that overall picture, and in most people, intercurrent episodes of exacerbation, in which there is a great upsurge in the severity of symptoms.

These episodes may last from days to weeks, and are usually triggered by some sort of physical (and sometimes emotional) stress: such as a viral illness e.g. 'flu, overdoing physical exercise etc.

'Flare-ups' are in essence the same sort of occurrence as the periodic exacerbations seen in many autoimmune conditions such as lupus or rheumatoid arthritis, and, indeed, the neurological condition which has some features in common with arachnoiditis: multiple sclerosis.

These episodes are most unpleasant, as well as being dispiriting and worrying.

As a general rule, once the symptoms subside, the usual level of pain and functional impairment resumes (this could be termed 'remission').

However, occasionally, there is a failure to regain this level of remission, and if episodes are frequent, there may be an apparent decline, with each subsequent 'flare up', or relapse, leaving the sufferer gradually more impaired.

A rather different picture may infrequently be seen in folk who are stable, but experience an event such as a fall, or a minor car accident, and who subsequently deteriorate (in a minority of cases, this may be a rapid and steep decline), without regaining lost ground.

Flare-ups can make life even more difficult than normal; generally though, they are self-limiting. Sometimes, however, it is important to remember that not ALL symptoms can be attributed to arachnoiditis.

Any consistently worsened or escalating symptom or indeed any persistent new symptom should be medically assessed to exclude conditions which are treatable.

Usually, though, it is a matter of riding the storm and waiting for it to blow itself out.

If possible, avoid the following:

- Staying in bed all the time
- Withdrawing from all activity: as we've seen, inactivity can lead to further problems, not least of which is feeling down because of all the things we can't do. Note that rheumatoid arthritis patients are encouraged to perform what is known as 'range of movement' exercises even in joints which are acutely inflamed; this is to maintain mobility; the same principle applies to people with arachnoiditis.
- Rushing off to the doctor: for most of the generalised symptoms of a flare-up, there is little a doctor can offer, except fairly standard advice;
- Reaching for medication; beware increasing doses 'as required'; if you need frequent higher doses than normal, consult your GP. Taking more medication than usual can lead to feeling sedated and perhaps confused; sometimes it is possible to take a dose having forgotten that you have already taken one; it is best to put out your day's tablets in a safe place or get a family member/friend to give them to you to avoid errors.

I will now list the 80 related medical condition listed by the American F.D.A.(1998) as the 'Cause-Effect of Iophendylate (Pantopaque) (Please remember it is said, that Myodil is the same chemical it's just a different brand name, being manufachured by another Company (Glaxo u.k.) in alphabetical order:

ALLERG REACT. AMNESIA. AMBLYOPIA.ANOREXIA. ANXIETY. ARACHNOIDITIS.

Asthenia. Ataxia. Atrophy muscle.

Brain synd crom.

Cardiovasc dis. Cns depress. Constip. Convuls. Cramps legs.

Delirium. Depression. Dizziness. Dysphea.

Edema. Periph. Emotion labil. encephalopathy.

Fever.

Gait abnorm. Gi dis.

Hallucin. Head pain. Heart arrest. Hem. Hematuria.

Hypertonia.

Incontin fecal. Incontin urin. Inject site recaction. Insomnia.

Intest per.

Joint dis.

Malaise. Migraine. Myalgia. Myasthenia. Myopathy.

Nausea. Neopl chs. Nervousness. Neuralgia. Neuritis.

Neuropathy.

Pain. Pain back. Pain chest. Pain injection site. Kidney.

Pain neck. Paralysis. Paralysis spastic. Paraplegia. Paresthesia.

Polyneuritis.

Rash. Reflexes dec, rhinitis.

SCLEROSIS MULTI. SEX FUNC ABNORM.. SHOCK. SKIN DISCOLOUR.

SPEECH DIS. SWEATS.

THINKING ABNORM. TINNITUS. TWICHES.
URIN RETENT. URIN TRACT DIS. URIIN URGEENCY.
VISION ABNORM VOMIT.

AUSTRALIAN ARACHNOIDITIS SUFFERERS QUEENSLAND ASSOCIATION INC
AASQA National Secretary
PH: (07) 55356655
e-Mail: petergroves@aaqa. info
Internet: www. aasqa. info
Mail: The Secretary
PO Box 1118
Palm Beach, Gold Coast
Queensland Australiana 4221

THE SECRETARY
A.A.S.Q.A.
P.O. BOX 1118
PALM BEACH 4221
PH. 5535 6655

Arachnoiditis

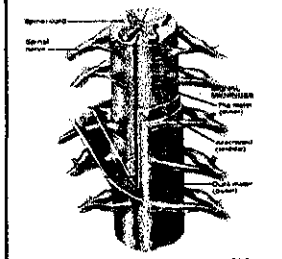
Neal Fitton

What is arachnoiditis?

The term arachnoid is derived from the Greek word archne (spider) and cides (shape) (1). The arachnoid is one of three membranes that surround the brain and spinal cord [2]. The arachnoid membrane is extremely thin and delicate and is referred to as a spider's web [3]. The brain and spinal cord are surrounded by three membranes [2]. The dura and pia membranes encompass the arachnoid membrane [2]. These membranes cover, protect and provide cushioning to the spinal cord and spinal cord roots [2]. (see figure 1.1) **Arachnoiditis is an inflammation of the arachnoid membrane** [4]. Davidson defines arachnoiditis as "Chronic inflammation of nerve root sheaths in the spinal canal" [5].

Figure 1.1

Spinal cord and spinal meninges



[6]

Causes

Arachnoiditis is caused by infections, trauma, spinal cord contamination, spinal cord tumors, and genetics [2]. Spinal cord contamination results from injecting foreign substances, such as steroids, contrast media, or antibiotics into an individual's body via the spinal cord [2]. The arachnoid membrane may not immediately become inflamed after the procedure [2]. It may take years for arachnoiditis to become evident [2].

Support and management strategies

Treatment is normally based on pain relief. According to Wright arachnoiditis can decrease the lifespan of a person by as much as 12 years [2]. Methods of treatment include:

- Pain management with narcotics [2]
- Steroids [2]
- Spinal cord stimulation [2]
- Surgical removal of scar tissue (sever cases) [2]
  (Surgical removal often results in only temporary relief and may cause more damage).
- Physiotherapy [4]
- Exercise [4]
- Psychotherapy [4]

THE SECRETARY
A.A.S.Q.A.
P.O. BOX 1118
PALM BEACH 4221
PH. 5535 6655

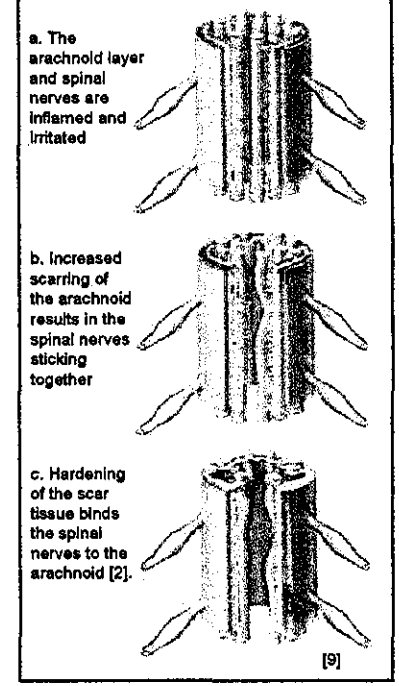
Nature and Progression

Unfortunately, arachnoiditis is an incurable disease. It has a sudden on set and diagnosis is based on symptoms and Magnetic Resonance Imaging (MRI) [6]. Arachnoiditis symptoms are difficult to distinguish from other diseases [2]. There are no set patterns for those who have arachnoiditis and symptoms vary in severity [1]. Arachnoiditis can reoccur even after successful surgery and if not treated will worsen [2].

Figure 1.2 points out the progression of arachnoiditis

Figure 1.2

Progression of arachnoiditis



[9]

Main characteristics

- Burning pain in the lower back and legs [2]
- Loss of sensation [4]
- Skin rashes and itching [2]
- Muscle cramps, twitches or spasms [4]
- Burning in the ankles and feet [2]
- Chronic pain, even at rest [2]
- Bladder and bowel control [4]
- Neurological defects [2]
- Sexual function [4]
- Numbness [4]
- Tingling [4]
- Stiffness in the neck [6]

Social and interpersonal difficulties

Patients who have arachnoiditis endure chronic pain [2]. This results in many people having a high risk of depression, suicide, and drug and alcohol abuse [2]. Social workers help in the recovery by giving advice on home, financial and community supports [6].

Common Psychosocial difficulties:

- Depression [7]
- Anxiety [7]
- Low frustration level [7]
- Irritability [7]

Australian support groups

Australia has two current support groups:

Australia Arachnoiditiis Sufferers Queensland Association (AASQA), http://www.asqua.org.au, and;

Australia Arachnoiditis Sufferers New South Wales association (AASNSWA), http://www.aasansw.org.au

Both support groups provide education, support, and promote

References
[1] Deshmukh, V, 2005, 'Arachnoiditis', Encyclopedia of Neurological Sciences, p 255-256, Elsevier Science Ltd
[2] Wright M, 2003, 'A comprehensive Review of Spinal Arachnoiditis', Orthopedic nursing, Vol. 22, Iss. 3, p. 215-219, Lippincott Williams and Wilkins, Hagerstown MD
[3] Grey, H, 1977,' Grey's Anatomy, The Classic Collector Edition, Bounty Books, New York
[4] National Institute of Neurological Disorders and Strokes (NINDS), 2007, Disorders, Arachnoiditis, Communications and Public Liaison, Bethesda MD, viewed 22 September 2008, <http://www.ninds.nih.gov/disorders/arachnoiditis/arachnoiditis.htm>
[5] Davidson, 2006, 'Presenting problems in musculoskeletal disease', Davidson Principles and Practice of Medicine, p 1085, Elsevier Ltd, India
[6] Neurologist Council of SA Inc, 2008 , 'Supporting people with Physical and Neurological Disorders', Spina Bifida and Hydrocephalus Association SA
[7] Eldon, T, 2008, 'Epidemiology of Chronic Pain With Psychological Comorbidity: Prevalence, Risk, Course, and Prognosis', Canadian Journal of Psychiatry, Vol. 53, Iss. 4, p. 224-234
[8] viewed 24 September 2008,
<http://faculty.etsu.edu/curtis/images/dura.jpg>
[9] Nucleus Medical Art Inc, 2008, Arachnoiditis of the Lumbo-sacral Spine-Medical Illustration, Human Anatomy drawing, particleweb, viewed 26 September 2008,
<http://catalog.nucleusinc.com/generateexhibit.php?ID=1669>

National Health Strategy

Hospitals

- A suggestion was made that there should be more watchdogs in Southport hospital and other hospitals especially concerning mental health.
- Hospitals can be made significantly less stressful by greater use of plants and art areas.
- Allied health workers should be included within the GP Super clinics.

Medication

Some participants indicated that there is scope for consideration of decriminalisation of marijuana for medical purposes..A comment was made that the Government should be aware that the enzyme Q10 can be used for preventative health.

Disease Recognition

Arachnoiditis should be recognised as a disease. The Australian Arachnoiditis Sufferers Queensland Association has been lobbying for its recognition. AASQA would like a Royal Commission into why the dyes that cause Arachnoiditis were used illegally and would like these dyes banned from use.

Health Insurance

A complaint was made regarding the need for health insurance, when twice upon request for a patient to be taken by ambulance to John Flynn Hospital, the patient has ended up at the public hospital, due to a "by-pass" order from the private hospital.

Aged Care

Today in Queensland, there are over 40 000 people suffering from Dementia. Many community organisations would like to see more people staying at home rather than in nursing homes. Accordingly, more support programs need to be available to relief the stress on families and carers, as well as a budgetary increase in the current commitment to the dementia programs.

The wages of care staff should be increased to attract new participants, with a recognition of the significant stress of the job.

- Some in the nursing care industry believe that there are insufficient resources to keep people in their homes, whereas there is an excessive number of CAP packages that are not being utilised.
- There needs to be a recognition of specific problems that young people face as carers, and there needs to be more support targeted towards younger carers.

A problem has been identified within the Hospital system in relation to the practice of recording high care patients as low care, due to the lack of high care packages available. This puts unnecessary stress on the staff and patient.

Arachnoiditis-The Silent Epidemic
Dr Aldrete arachnoiditis.com
Arachnoiditis Foundation, Inc.

Pg 215 Commentary at the end of chapter on Clinical Diagnosis

"Since the most common cause of ARC is usually an iatrogenic event resulting from a complication of a diagnostic or theraputic procedure, the medical community must therefore take an introspective look at itself without skeptisicm and reluctance, There is little doubt that today, interventional procedures of the spine are the etiologoy of most of these cases. We must recognize the severity and chronicity of the consequences that such morbidity produces, includin life-term suffering suffering, psychological dysfunction, and physiacl disability in these patients, representing a huge cost to the healthcare system. The majority of teh patients in this series were not wrking, required assisted care, made, frequent doctor visits, and underwent procedures that only produced temporary pain relief. Eventhough most of them were taking a myriad of medications(among which controlled substance predominated), they continued to experience severe pain.
Once this premise is accepted, we can explore and achieve specific protocols to avoid this complacation.In order to fully understand ARC, we must correlate the clinical manifestations with the path of their transmission and reception. Contrary to what other authors claim, in caring for these patients, we must realize that it is primordial to make thoughtful and objective decisions regarding interventional diagnostic or theraputic modalities of the spine concerning their long-term outcome. For any procedure, odds of 40%or 60% success are unacceptable when there is a high rsk of morbidity. In other words, their indications have to follow the premise"prima non-nocere"-if they do not help the patients illness they certainly should not hurt them.
Although symptoms of ARC are not specific, they are very real and suffering patients bear them every day. Hopkins recently did a survey and reviewed her own symptoms and those symptoms experienced by other patients;the drmatic report served as her Thesis for a Master's Degree in Nursing and is indeed revealing-it is a story shared by most of my patients."

THIS MAN IS CALLING A SPADE A SPADE AND THIS BOOK IS AN AFFRONT ON HIS COLLEGUES AND WHAT THEY ARE DOING TO US. HE SAYS IT IN THE MOST PROFESSIONAL WAY WHAT HIS PEERS ARE LACKING. I BET THAT HE IS NOT A FAVORITE IN THE MEDICAL COMMUNITY BECAUSE HE IS GOIG AGAINST THEM AND SIDING WITH THE PATIENTS.
THE BROTHERHOOD IS UNFORGIVING AND I WOULDN'T DOUBT IF THER IS A CONSIRACY AGAINST HIS CHARACTER TO TRY TO DISPELL THE VALIDITY OFWHAT HE SAYS.
THE WHOLE BOOK IS WRITTEN IN SUCH A WAY WITH A COMMENTARY AT THE END OF EACH CHAPTER.
WE ALL NEED OUR OWN COPY.
yOU CAN GET IT AND HIS # AND ADDRESS AT arachnoiditis.com

If you would like to purchase
"Arachnoiditis: The Silent Epidemic"

Special price for Arachnoiditis sufferers is now $25.00.
Price for healthcare providers and attorneys is $50.00.
Shipping and handling is $4.00.

Now accepting VISA and MASTERCARD over the telephone. Please call for your orde
r (205) 968-0068.

For mail orders please send a check to:
J. Antonio Aldrete, M.D., M.S.
P.O. Box 4627
Seaside, FL 32459-4627

Following is the table of contents of Dr. Aldrete's newly-published book "ARACH
NOIDITIS: THE SILENT EPIDEMIC," which describes the
concepts expressed in this website in-depth with a supportive medical bibliogra
phy:

V. Etiology

A. INFECTIONS: At first, the earlier cases of ARC were caused by sy
philis, tuberculosis, meningitis, influenza, etc. Lately, echinoccocus,
cryptococcus, and the AIDS virus have been the most frequent origin of it.

B. MYELOGRAPHY: Reviews how oil-based and also some water-based dyes
used for myelography caused innumerable cases of ARC
from the 1940's to the 1990's.

C. BLOOD IN THE INTRATHECAL SPACE: Under certain circumstances, blood
in the subarachnoid space acts as a chemically-irritant
factor producing ARC.

D. ANESTHETIC SUBSTANCES IN THE SPINE: High concentrations of anesthe
tic substances or prolonged exposure of neural tissue to
lower concentrations, as well as direct trauma to spinal cord or nerve roots du
ring injection produce a variety of lesions varying from cauda
equina, radiculitis, transient nerve root irritation, etc., some of which end u
p in ARC.

E. SPINAL SURGICAL INTERVENTIONS: Surgical interventions of the spin
e appear to leave a higher than expected incidence of ARC
(between 15 and 20%) due to the entry of blood into the subarachnoid space thro
ugh inadvertent rents or recognized tears of the dural sac.
Pseudomeningoceles, leaks of CSF, epidural abscesses or postoperative hemorrhag
e are surgical complications that frequently ensue in ARC.

V. EtiologY (cont)

F. CORTICOSTEROIDS: Corticosteroids have been the subject of great d
ebate as to causative agents of ARC, while at the same time
being the optimal anti-inflammatory medication. The controversy going on for n
early 30 years is put to rest in this chapter, as it defines the
concentration of the preservatives contained in the various preparations of ste
roids as the culprits, and emphasizes the indications for
corticosteroids in the inflammatory and the proliferative phases of ARC.

G. TRAUMA: Trauma of the spine is identified as a possible cause of A
RC, especially when there is considerable hemorrhage in the
subarachnoid space as well as spinal cord and/or nerve root injury. Emphasis i
s placed on the opportune early use of corticosteroids in reducing
subsequent neurologic deficit.

VI. Other Forms of Arachnoiditis

A. OBLITERATIVE ARACHNOIDITIS: Obliterating forms include Arachnoidit is Ossificans and Pachymeningitis, which are extreme presentations of ARC.

B. SYRINGOMYELIA usually consists of cavitary intramedullary lesions l ocated in the spine, which may interfere with the normal circulation of the CSF.

C. OPTOCHIASMATIC ARACHNOIDITIS includes visual field alterations with endocrine disturbances since it affects the chiasma and the pituitary gland.

D. CEREBRAL ARACHNOIDITIS is frequently caused by chronic, uncontrolla ble infection of the cranial frontal, maxillary, or sphenoid sinuses, or the mastoid cells in severe chronic otitis media. In addition to n eurologic deficits, cranial nerve disturbance, atypical facial pain, and headaches can be found with common psychogenic manifestations.

VII. Questionable Causes of

Arachnoiditis

A. SPINAL STENOSIS: Spinal stenosis has been suggested as a form of A RC because there appears to be apparent nerve root clumping in neuroimaging studies; the concept is refuted, however, since there is no acu te inflammatory phase, and the pseudo-clumping of the nerve roots frequently disappears after decompressive procedures of the spine.

B. FOREIGN BODY REACTION: Foreign Body Reaction has been proposed as a cause of ARC when gauze, suture materials, talcum powder, glues and other materials have been inadvertently or purposefully left in the intrathecal space.

C. HERNIATED NUCLEUS PULPOSUS: Constrictive or cystic lesions of ARC have given the clinical and radiological impression of intraspinal tumors. On the other hand, some tumors of the spinal structures ma y appear to be ARC. Occasionally, primary or metastatic lesions invade the meninges, resembling ARC.

VIII. Diagnosis of Arachnoiditis

A. CLINICAL DIAGNOSIS: The clinical signs and symptoms of ARC are descri

bed, including the localized and systemic manifestations as they appeared in 162 patients with radiologically confirmed ARC. Their possibl e mechanisms and paths through the posterior horn of the spinal cord and the ascending spinal tracts are discussed.

B. LABORATORY AND RADIOLOGICAL DIAGNOSIS: Few laboratory studies have been shown to be of any use in diagnosing or confirming the presence of ARC, nor have the electrophysiological tests proven to be reliable for this purpose. The precise diagnosis of ARC has been shown mostly by carefully-performed and interpreted MR imaging, especially with contrast media. The indication for plain radiographs and CAT scan after myelography is discussed. The possible role of myeloscopy as a diagnostic tool is mentioned. Contains 33 images representing this disease.

IX. Prognosis

Being incurable, ARC has a poor prognosis since patients are usually affected f or life, with considerable pain, physical and sexual dysfunction, and common emotional disturbances (especially depression). Discusses patient g roups as means of improving outcomes. The advantages of the Internet as well as the disadvantages of transmitting incorrect information are also addressed.

X. THERAPEUTIC OPTIONS

A. MEDICAL TREATMENTS are mostly symptomatic including analgesics, ant idepressants, muscle relaxants, anti-inflammatories and anticonvulsants. However, there is a definite strategy in the indications for each of these agents at the various phases and stages of ARC. The role of physical therapy and holistic approaches are discussed. The interventi ons of psychotherapy, when needed, are emphasized.

B. INTERVENTIONAL PAIN RELIEF PROCEDURES: Epidural and intrathecal in jections and long-term infusions are discussed, as well as specific indications and possible benefits. The pros and cons of adhesiolysis and neuroplasty procedures are debated.

C. ELECTRICAL STIMULATION OF THE NERVOUS SYSTEM: Dorsal column stimul ation in its various forms is discussed defining its specific indications as well as deciphering the results in the series already p ublished. Acupuncture and TENS unit therapy are addressed. The possible role of cerebral electrical stimulation is noted.

D. SURGICAL TREATMENT: Advocated off and on for nearly 100 years, the reports usually consists of a few poorly-selected and not consistently treated cases. However, the new combined approach, including selective medical treatment, preemptive analgesia, microscopic lysis of adhesions and the use of adhesion-preventing materials appears to be more promising.

XI. Future Prospectives

The understanding of the various phases of ARC, its pathophysiology, and the need for prompt diagnosis constitute the basic triad that would lead to the education of physicians and other health care providers aiming at preventing this disease, which is acquiring epidemic proportions. The many prospective research avenues are noted as possible means of preventing and treating arachnoiditis are mentioned as well as means of how to improve the patients' quality of life.

Written by [illegible]
Thursday, 21 April 2005

I thought I ought to add a little addendum to the How the Dye was cast piece: namely that last year I found on the net, a Paediatric text book from 2003 from Papua New Guinea detailing use of myodil in babies, using 3,6 or 9 mls and not aspirating.

the reference url for the Papua NG is:

Paediatrics for Doctors in Papua New Guinea 2nd. Ed.
http://www.developmentgateway.com.au/health/paediatrics

direct copy of p.233:

MYELOGRAM

Do not attempt this if the child has raised intracranial pressure.

1. Perform a CAREFUL lumbar puncture (p.1). This may be difficult to do if there is a spinal block and a lumbar puncture has been performed recently. Cisternal puncture (p.80) may then be necessary.

For this reason, NEVER do a lumbar puncture in a child with a suspected cord lesion until the time of the myelogram.

Send the CSF for micro, culture, protein, glucose, AFB and Indian ink.

It is important to be sure that the lumbar puncture needle is correctly placed, to avoid injecting dye outside the subarachnoid space.

2. Inject iophendylate (Myodil), then remove the lumbar puncture needle:

Infant:

Child:

Adult:

3 ml

6 ml

9 ml

3. Turn the patient prone. Always keep the head EXTENDED. Myodil is heavier than CSF, and can be made to run up and down the spinal cord by tilting the head or feet down.

NEVER allow Myodil to enter the head.

a. fill the region with Myodil as much as possible by tilting the table

b. take a PA and lateral.

5. If an obstruction is encountered:

a. take a PA and lateral immediately

b. increase the head down tilt and wait 2 minutes, hoping the Myodil will run into the obstructed area to give a better outline. If it does, repeat the PA and lateral films

c. if the Myodil passes the obstruction, tilt the feet down to outline the upper end of the block.

Repeat the PA and lateral films.

6. It is not necessary to remove the Myodil after you have finished the examination.

Also there is a website from Egypt which mentions use of oil-based dye being 'less common' than before which implies it is still going on!

Egyptian ref:

Cairo University School of Medicine Atlas of X-ray

re: Myodil myelography..."not done as frequently as before after the introduction of MRI" not sure of date though.

Last Updated (Thursday, 21 April 2005)

Egyptian ref:

Cairo University School of Medicine Atlas of X-ray

re: Myodil myelography..."not done as frequently as before after the introduction of MRI" not sure of date though.