

## **AARMOR**

### **REPORT ON THE FIRST INTERNATIONAL CONGRESS ON ARACHNOIDITIS AND TARLOV CYSTS**

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## **Background of the Congress: it's origins**

**AARMOR** (Association for Arachnoiditis and other Orphan Diseases) was created in 2008 in an attempt to support patients with these conditions and to raise awareness in France of pathologies such as arachnoiditis, Tarlov and meningeal cysts. Muriel Gendre, the President of the organisation, conceived the idea of a congress to spread the word.

The Tarlov support group was set up in 2002. Claudine Goze-Weber, from TarlovEuropeInformation, became an ally, assisting Muriel in preparing for the congress and

translating texts written by the lecturers so that a comprehensive guide to the congress could be made available to attendees.

### Barriers to the congress

Despite scepticism from quite a number of people prior to the congress, with suggestions that it would never take place, and questions about funding, the organisers forged ahead and brought their plans to fruition, perhaps against the odds, given that firstly, Muriel and Claudine worked at a distance from each other; secondly, they had never done anything of this nature, and lastly, but by no means least, they both have to cope with the illnesses that the congress is about. Fortunately for all those who could attend, their persistence was successful.

### Attendees

**CIPMADN** (Congrès International des Pathologies méningées Arachnoïdite Syndrome de la queue de cheval Et Douleurs neuropathiques) was something of a first on more than one count. Not only was it the first congress on these conditions, but it also brought together both professionals and lay people (patients) which is highly unusual. Amongst the Doctors there were representatives from the Americas and Europe, from a variety of disciplines with a common goal of trying to help patients with arachnoiditis and/or Tarlov cysts. Speakers: also came from non-medical backgrounds, many with the conditions they spoke about. The audience comprised patients and their families/friends from all around the world who travelled despite the difficulties.

### What is arachnoiditis?

Most people think it must be something to do with spiders...in fact it is a chronic inflammation and scarring of the middle layer of the meninges, which line the spinal cord and brain. In most cases, it is spinal, although there are some patients with cerebral arachnoiditis.

The name derives from the term 'arachnoid' which relates to the appearance of the meningeal layer, as it resembles a spider's web.

Essentially, arachnoiditis damages the affected nerve roots, causing them to clump together like over-cooked spaghetti.

Dr Charles Burton described arachnoiditis in his Burton Report in 2006, as a "scientific orphan". He remarked "***this disease entity remains essentially unknown, unreported and unrecognised***", echoing the words of French some 60 years previously who noted "failure to recognise...has resulted in fathomless confusion."

Professor Antonio Aldrete, an expert in the condition and author of two books on it (the most

recent published this year (“**Arachnoiditis: The evidence revealed**”) spoke to the congress about historical aspects of arachnoiditis.

He described an ‘epidemic of cases of arachnoiditis’ appearing in waves: the era of infection (Charcot’s 19th Century work in Paris) followed by the era of intrathecal injections (local anaesthetics, by doctors such as Biers) and then the era of surgical exploration (Horsley in particular conducted experiments which made the neurosurgical community aware of this ‘new’ illness).

In the early 20th century, pathologic neurology such as the Foix-Alajouanine Syndrome appeared and subsequently the era of diagnostic radiology, using the toxic myelographic dyes predominated throughout the rest of the century.

Aldrete further comments in his book that there continues to be, ‘**unfolding in controversy,**’ of other eras of iatrogenic cases of arachnoiditis.

Professor Jan Warnke, a neurosurgeon from Germany, spoke about the pathology of arachnoiditis. He illustrated his talk with images that explained in detail the type of problem he typically sees at operation (he conducts thecaloscopy, using a fine telescopic instrument inserted into the affected area).

Prof Warnke explained that the function of the arachnoid is to maintain the CSF in place, to act as an elastic absorber of the CSF flow, and at the arachnoid angle, to act as a valve to release CSF at the nerve rootlet as it exits the subarachnoid space. He pointed out that the healthy arachnoid cannot be imaged with CT or MRI although inflammation can be seen with contrast enhanced MRI.

There are different types of arachnoiditis depending on the triggering cause; broadly the categories are:

1. Mechanically-induced (post-surgical, traumatic etc.): usually localised
2. Chemically-induced (epidural/intrathecal injections of various types): may be multi-level
3. Infectious (meningitis, TB)
4. Miscellaneous (e.g. subarachnoid haemorrhage)

Further details on some of these causes are to be found below

Onset of symptoms may be early (as described by Auld in 7 post-operative cases and Bay in patients after intrathecal chemotherapy) or delayed (e.g. Benner & Ehni reported post-surgical cases, Etchepare a case of 17 year delay after a traumatic lumbar puncture and various authors have reported prolonged delay after myelogram: up to 30 years).

There may be acute symptoms, arising suddenly, e.g. after a fall, or chronic, gradual

symptoms. The trigger for the onset is often fairly minor, a slight fall or other illness.

Patient Sandy Asche, who spoke of her experience of the condition at the congress, also contributed the following description in Aldrete's book: ***“the slip of a foot and the forceful snap of another body into mine, as I was assuming an awkward position, had become the one second in time that changed my quality of life from vibrancy to devastation.”***

Arachnoiditis does not present with a typical clinical picture which leads to problems with recognition. Aldrete reports in a 2006 article ***“severe, unrelenting pain”*** as the predominant symptom and certainly the postal survey of online support groups in 1999 echoed this. Other symptoms included sensory deficit, weakness, muscle cramps, stiffness, fatigue, joint pain, balance problems, reduced mobility, bladder/bowel/sexual dysfunction, excessive sweating, depression etc.

Experts disagree on whether arachnoiditis is progressive. Medical literature is unclear and estimates of the percentage of patients with progressive symptoms seem to vary widely. Patients with arachnoiditis often say they think it is progressive. In the Database 42/61 felt this.

In Guyer's 1989 paper, 59% felt the same, 33% worse and 7% better compared with when they were diagnosed. 18 months later, 21% felt the same, 29% felt worse and 50% felt better.

There are a number of ways in which the condition may appear to progress, although the pathology is unchanged: these include development of a chronic pain syndrome secondary to the condition.

There are also a number of possible complications, which include syringomyelia, arachnoid cyst and hydrocephalus.

### **What are Tarlov cysts?**

The Congress was fortunate to be addressed by neurosurgeon Professor Edward Tarlov, son of Dr Isadore Tarlov who discovered the perineurial cysts on lumbosacral nerve roots in 1938.

Dr Tarlov suggested in 1948 after surgical exploration of the lumbosacral area, that these cysts could cause sciatica. He found the cysts in about a third of his autopsy dissections.

Professor Tarlov therefore commented in his talk at the Congress that in fact there must be quite a large number of Tarlov cysts in the world population.

However, he pointed out that sciatica is an extremely common symptom and that there may be a variety of other more likely causes than sacral cysts. Although the perineurial cysts often cause bony erosion of the sacrum, the pressure being exerted is akin to that of water dripping on a stone, causing effects over a prolonged period of time. The cysts often communicate freely with the subarachnoid space, which Prof Tarlov suggests can further complicate the

origin of any symptoms.

Dr Maitrot from Alsace, described symptoms from Tarlov cysts arising from compression of nerve roots, progressive denervation of the affected nerve roots in the cyst, cauda equina compression and venous effects causing oedema. He showed images of single, multiple, true and pseudo-Tarlov cysts. CT is investigation of choice and myelograms with delayed imaging (to show filling of the cyst with dye).

Dr Maitrot mentioned the SCNLF Congress in 2000 ("Société de NeuroChirurgie de Langue française") admitting that this was when he first realised he might not have been adequately assessing his Tarlov patients. He delineated some of the symptoms seen in various case series, including back and sacral pain (often worse at night), radiculopathy (sciatica), perineal pain, weakness and sensory deficit, bladder dysfunction (often urinary urgency and pain on micturition).

### **Similar and related conditions.**

As already mentioned, arachnoiditis tends to present with non-specific symptoms that could be caused by other conditions and as we can see above, Tarlov cysts also cause symptoms that can be confused with those due to other, commoner problems. Not only that, but other, mechanical problems, widespread within the population, may be present alongside the rarer conditions which can further confuse the clinical picture.

The Congress in fact opened with a talk by Dr Jacques Beco, a Gynaecologist and Perinealogist from Liege in Belgium.

Dr Beco described pudendal neuropathy which is due to the pudendal nerve being affected. There are some striking similarities with Tarlov cysts in terms of presenting symptoms and indeed there are also some similarities with certain cases of lumbosacral arachnoiditis. Dr Maitrot later agreed with Dr Beco that pudendal neuropathy can be a feature of Tarlov cysts.

Dr Beco outlined the principal symptoms of pudendal neuropathy: perineal pain including vulval pain, proctalgia fugax (shooting pains in the rectum), pain while sitting as well as gynaecological, urological and colorectal problems. He explained that the condition remains unrecognised in many patients, but suggested ways in which doctors can establish the diagnosis. Clinical examination is key, particularly using a gynaecological examination position (Lithotomy) which most orthopaedic or neurosurgeons don't know to use.

He also pointed out 3 clinical signs: abnormal pinprick test, skin rolling test and painful pudendal nerve during rectal examination. Investigations such as EMG, Doppler of the pudendal arteries and MRI of the ischioanal fossa can all help to confirm the diagnosis.

Dr Maitrot delineated different causes for sphincter dysfunction (bladder/bowel):

- Central: brain lesions such as stroke, Multiple Sclerosis, brain tumours, Parkinson's
- Spinal: e.g. trauma, congenital problems
- Nerve/root lesions: prolapsed discs, spinal stenosis, tumours etc. also arachnoiditis
- Tarlov cysts
- Neuropathies including pudendal and post-delivery

Professor Aldrete and Dr Godinez presented a talk about Failed Back Surgery Syndrome (FBSS), of which arachnoiditis is one of the causes. Other commoner causes include recurrent disc herniation, spine instability, cysts etc. The leading cause for FBSS is inadequately treated lateral spinal stenosis.

Dr Godinez noted that 5-40% of patients having spinal surgery may develop FBSS and that 20-30% of patients require further spinal surgery within 4 years. The prevalence of FBSS is >25%. Dr. Charles Burton has suggested that 11% of FBSS cases are due to arachnoiditis.

Dr Godinez quoted Finneson: ***“No matter how intense or resistant to treatment is pain, surgery can be worse.”***

Factors suggesting a worse outcome include symptoms lasting more than 6 months before surgery, smoking, alcohol, obesity, diabetes, hypertension and multiple previous treatments.

Other significant factors include: congenital spinal abnormalities, sacralisation of L5 or lumbarisation of S1, facet joint arthropathy and ligamentum flavum hypertrophy.

Persistent post-operative back or leg pain (FBSS) can arise as a result of diagnostic errors, errors in choice and implementation of surgical technique and operative complications (e.g. bleeding, infection).

Sometimes surgery is performed when it is not indicated, in other cases, there may be multi-level pathology which is not amenable to surgical treatment at a single level. There may also be unrecognised and untreated pre-existing segmental instability.

In cases of post-laminectomy syndrome (PLS), assessment should be made of the relative intensity of the back and leg pain: back pain is not generally well treated by surgery whereas leg pain (sciatica) tends to respond more favourably and might warrant a further surgical intervention.

Psychological and socio-economic factors are also part of the FBSS picture.

Dr Godinez concluded that correct patient selection is critical in avoiding FBSS. A multidisciplinary and multimodal approach is needed in treating cases of FBSS.

### Causes of arachnoiditis

Arachnoiditis has a variety of causes, many of which are iatrogenic, i.e. caused by medical interventions.

Prof. Aldrete outlined the historical aspects of arachnoiditis, noting that trauma and infections were the commonest cause of death in ancient times. Arachnoiditis is known to be associated with TB even nowadays. In his talk, he went on to discuss the more recent causes, including spinal injections of anaesthetic etc.

Prof Renck noted that pre-1990, literature on adverse effects of spinal anaesthetics were limited to case reports. There were various hypotheses to explain this: such as continuous blocks causing prolonged exposure and increased pressure in the epidural space.

He then presented data from the 2004 Swedish study by Moen et al which looked at complications of central nerve blocks in the 1990s. During the decade studied, there were 127 serious neurological complications of which 85 involved permanent damage. Complications were most common in orthopaedic surgery and fewest in obstetric patients.

Focussing on cauda equina syndrome, of 32 patients, toxicity of local anaesthetic agents was blamed in 23 patients.

Prof Renck commented that although the numbers are low, as compared with other causes of morbidity and mortality, incidence could be lower and that ***'careful and responsible anaesthesia praxis must always be aimed at.'***

Dr. Holder, in her talk about the effects of blood in the CSF, stated that the incidence of complications is under-estimated. She reported that epidurals carry more risk than spinal (and a 4 times greater risk of haematoma/abscess). She suggested that most cases of cauda equina syndrome and arachnoiditis result from the 'wrong drug' (i.e. containing contaminants etc.) being injected into the subarachnoid space.

Arachnoiditis arises as a result of infection, bleeding, trauma, ischaemia of the nerve root, chemoneurolysis and chemical meningitis caused by preservatives and preparatory solutions.

Undiagnosed pre-existing conditions such as asymptomatic cysts carry an increased risk. Repeated attempts give a higher risk of haematoma and infection. Conditions (such as placental abruption, foetal demise) that cause clotting disorders also increase risk of haematoma.

Dr Holder reported that the incidence of post dural puncture headache (PDPH) is as high as 85% with a 16-18 gauge needle in pregnant women. PDPH was first described by Sicard in 1902 and in 1956 a more detailed description by Vandam & Dripps (in JAMA) described an overall incidence of 1.5-6% in all the population.

PDPH results when the CSF pressure drops as a result of leakage through the accidental puncture. The headache is typically very severe.

**Risk factors for dural puncture:**

- Obesity
- Patient movement (common in later stage labour)
- Spinal stenosis
- Compression fracture
- Previous spinal surgery (loss of epidural space due to scarring)
- Scoliosis (curvature of the spine)

The treatment for PDPH, an epidural blood patch (EBP), involves drawing blood from the patient's arm and injecting it into the site of the original epidural injection. A second dural puncture is possible when performing this procedure and it is difficult to target the blood precisely. The aim is to plug the leak of CSF. Other treatments for PDPH include intravenous caffeine, and use of hypotonic fluid to replace the CSF.

Dr Holder pointed out that, contrary to common practice, EBP is not effective as a prophylactic measure to prevent headache after an accidental dural puncture, nor is it effective immediately after the event; it is best administered at day 4.

She noted the Diaz review (1995-2006) which recommended restricting the volume of blood injected to less than 20ml, restricting the number of patches to 2 or less. Diaz noted there was a direct relation between the volume of blood injected and worsening neurological problems. Blood is highly irritant to nerve tissue. (Arachnoiditis: The evidence revealed" Editor ALFIL ? mEXICO isbn 978-607-7504-25-2 chapter 27 pae 349 to 362 )

Szeinfeld stated that 1.6 ml of blood will spread within one spinal segment (typically 12-18ml are injected). Blood tends to spread cranially (towards the head) rather than caudally (towards the feet).

Dr Holder went on to outline the Kuczkowski protocol to reduce the incidence of PDPH:

- 1) Injection of CSF back into the subarachnoid space at the time of dural puncture
- 2) Insertion of intrathecal catheter
- 3) Infusion of 0.0625% bupivacaine (a local anaesthetic agent) and fentanyl (morphine related painkiller): an initial bolus followed by an infusion over up to 24 hours.



She further discussed treatment of blood in the CSF, recommending an MRI with contrast, bed rest (noting that after EBP patients should remain lying down for at least 4 hours to keep the blood clot adhered to the dural puncture hole). She suggested further measures (discussed later in the section on treatment).

Dr Holder noted that epidural colloids such as dextran 40 given by bolus or infusion would be a better alternative to EBP.

Common complications of EBP include backache, nerve root pain/tingling, neck stiffness and abdominal cramping. Arachnoiditis is less common but the incidence under-estimated. Other less common complications include cauda equina syndrome, meningitis, and epidural abscess.

Persistent CSF leaks can also be a problem. These may cause a number of symptoms including transient hearing loss or double vision.

### **The experience of chronic pain (Dr Fox)**

### **Arachnoiditis (Dr Fox, Sandy Asche)**

### **Tarlov cysts (Vigdis Thompson, Terri Reasoner and Brigitte Seuser),**

### **Claudine Goze**

As Albert Schweitzer said, ***“Pain is a more terrible lord than death.”*** Yet pain is a basic survival mechanism, a signal of danger. Acute pain can save life, but in chronic pain it is no longer useful and becomes a complex set of problems that have profound effects on all aspects

of day to day lives.

Pain mechanisms are highly complex and our understanding of the nervous system changes all the time. Contrary to previous ideas, we now know that the nervous system is highly changeable ('plastic') and that in chronic pain, there can be a 'wind-up' of pain perception at a spinal level as well as changes within the brain.

There is a strong logical and biological link between pain and anxiety/depression because pain and mood involve the same brain areas. As a result, there are hormone, immune and autonomic effects which cause widespread symptoms that are often poorly understood by patients and healthcare professionals alike. There can be a range of often bizarre symptoms that lead patients to question their own sanity and doctors to be disbelieving. Over time, a vicious cycle of events can lead to increasing disability.

Patients turn to doctors for help, but unfortunately, chronic pain tends to respond poorly to treatment. It can be very difficult for people to come to terms with the intractable nature of their pain, especially as we live in an era of high expectations, fed by media, with highly unrealistic adverts for 'painkillers' (a real misnomer).

As Prof. Joanne Dahl has commented ***"Pain that is unavoidable is bearable, but pain which is avoidable becomes unbearable."*** Unfortunately, pain doctors may inadvertently add to the problems with a variety of interventions, particularly invasive ones, which may cause arachnoiditis or make it worse.

In a second talk, Dr Fox went on to look at how arachnoiditis affects lives. Much of her understanding of the condition comes from her own experience of the condition as well as contact over the past 12 years with a number of support groups around the world, most notably TheAword.org which is run by Kim Nevitt, but also COFWA in the US, ASAMS in New Zealand and a number of other smaller groups in the UK, Australia etc.

There are different types of arachnoiditis, depending on the initial cause. Mechanically-induced arachnoiditis arises after surgery, trauma etc. and tends to cause localised scar tissue, whereas chemically-induced arachnoiditis (from dyes, spinal injections, etc.) usually has a wider effect.

Other causes include infection, bleeding into the spinal fluid during strokes etc. Many cases have more than one cause.

Onset of arachnoiditis can be early or delayed (by up to 30 years!), acute or chronic. Patients who have had an oil-based myelogram, for instance, may be unaware of the sword of Damocles which lies in wait for them.

The trigger for the onset may be what seems to be a minor event such as a fall, or further surgery. There have been a number of documented cases of this phenomenon. Dr Charles Burton has suggested what he calls the 'giraffe neck' effect which is based on the idea that the nervous system adjusts to gradual change but cannot acclimatise to sudden change.

Guyer's 1989 seminal paper on prognosis suggests that the majority of patients with arachnoiditis have a **“disabling disease causing intractable pain and neurological deficits.”** There are various patterns of symptoms, some constant, some fluctuating with periods of flare-ups and relative remission (similar to MS).

There is no typical presentation but in general, back and/or leg pain is present, often with change in sensations, weakness, muscle cramps, stiffness, fatigue, balance problems, etc.

Many patients 'plateau out' and remain stable, but a few may have rapid deterioration after an event such as a fall. Weakness, bladder and bowel dysfunction seem to occur in the progressive cases. Symptoms are affected by factors such as weather changes, temperature, emotional or physical stress, and either immobility or conversely, exercise.

In her thesis, Christine Hopkins found a **“high level of disability linked largely to pain, as an immobilising factor in their lives”** in the eleven patients she interviewed.

Dr Bourne, who published a paper in 1990, no doubt informed by his wife's experience with arachnoiditis, described **“the relentless and progressive pain syndrome of arachnoiditis.”**

There are a number of reasons why arachnoiditis can appear to progress: the initial underlying spinal problem may progress, there may be secondary muscle problems, especially if mobility is poor. Pain may increase over time due to 'wind-up' and a 'chronic pain syndrome' may develop. Add to that the side effects of medication and any other medical conditions and it is easy to see that arachnoiditis can exert an enormous impact on quality of life.

Experts such as neurologist Dewey Nelson, and Dr Charles Burton (neurosurgeon) both suggested that the patients who do best over time are those who remain as mobile as possible and take as few strong painkillers as possible.

Treatments are of limited palliative effect, with no cure currently available. Many patients take a cocktail of strong drugs to combat pain and other symptoms but these can then cause more problems with side effects.

Many are unable to carry on working and need to claim disability benefits. Often people become isolated and have a poor quality of life, for some to the extent that life no longer seems worth living.

Nevertheless, despite **“sunrises of sweaty exhaustion and evenings of cold dread”** (Sandra Asche 2007 in Aldrete 2010) many people with arachnoiditis display considerable fortitude and courage. As the late Dr Wendy Anderson (who had arachnoiditis) wrote **“I have discovered that good quality of life is possible when the focus is not on personal pain but on positive opportunities arising from the most adverse circumstances.”**

Sandy Asche's talk combined insight into the frustrations and uncertainties of contemplating a future with arachnoiditis with a very positive report of the benefits she has had from a number of different treatment strategies. From medical hints of euthanasia to 'total pain has been reduced by 75% and daily function has increased by 75%' took Sandy along surgical and medication paths, as well as visiting chiropractic, and common sense measures such as loose clothing, application of moist heat etc. Sandy has developed an arsenal of treatments for the different types of arachnoiditis pain, but she admits that **‘after one finds answers, the questions change.’** And that the

future is still uncertain. ..

**.’the only constants are change...and pain.’**

Nevertheless, Sandy concluded that **‘life is beautiful. It's not heaven yet, but it is certainly not the hell it has been in the past.’**

Brigitte Seuser, of the European Tarlov Cyst Alliance, presented her qualitative study of living with Tarlov cysts. In much the same way as arachnoiditis, symptomatic Tarlov cysts impact on all areas of everyday life. The continual chronic pain and the uncertainty of what symptom will strike next have a profound impact on quality of life.

Tarlov cysts share with arachnoiditis the effects on mobility, causing increasing difficulties with physical activity progressively throughout the day. Overdoing it always carries a penalty and people feel they need to constantly bear in mind their limitations in order to avoid further increasing their suffering. Lifestyle may change to accommodate the new restrictions imposed by the condition: often people become isolated.

Changing things for the better may involve tracking down a health professional who will recognise, understand and help manage the problems. There may be difficult decisions about which treatment to embark upon, with complex medical issues to consider. There may also be a risk of complications. In some countries, financial implications (the need to fight for insurance payment) add to the burden of problems.

Fortunately, Internet support groups can offer a great source of support and assistance.

Vigdis Thompson from Norway also gave a highly interesting personal account of her experiences with Tarlov cysts. As with so many people, she has experienced obstacles within the medical field and also on financial issues. Unable to find the necessary treatment in her homeland, Vigdis had to travel to the US where she underwent surgery under the care of Dr Donlin Long. Through determined perseverance, Vigdis recently helped her friend Heidi to become the first patient in Norway to undergo the surgical procedure AFGI. Vigdis, with the help of her manual therapist, has been spreading the word about the condition and is involved

with the Back Pain Support Group (who publish a journal called **Ryggstøptten**). Vigdis is also part of a small group who can be found online: "**www.ryggforeningen.no**".

Terri Reasoner from California looked at the ways in which people use an online support community to support living with chronic disease. The Tarlov cyst website was founded in 2000 and has since been a resource providing information and support. There are now about 1800 members and around 5000 annual posts to the site. There are moderators and bye-laws to ensure smooth running, and the site does not promote specific medical advice or treatment.

As Terri explains in her thesis, often people with Tarlov cysts encounter many obstacles before they find out what is wrong, and may undergo medical procedures that do not provide the intended benefit.

Terri's collective story relates many symptoms reminiscent of those experienced by people with arachnoiditis: stabbing, burning sensations, walking on nails etc. resulting in difficulties with daily tasks. The reality of the physical pain and its exhausting effects are matched by the roller-coaster emotional effects.

The participants in the study talk about extreme effects on their quality of life, which is whittled down to a focus on when the next medication is due. There remain, however, concerns that the suffering is all in their heads. One of the biggest challenges has been to track down a doctor who will listen and try to help.

Often, turning to the Internet is the only way forward people can perceive. Discovering others with similar problems and feeling validated has been as powerful as the information they seek and find on the website, that they have been unable to find elsewhere.

The Tarlov talk forum has been instrumental in many new friendships (note there is a similar forum on theAword.org for people with arachnoiditis). Although participants may initially feel reluctant to join in, over time they become comfortable and comforted as part of this community. Being isolated at home, and often even feeling so within their family and friends, here, online, they feel valued and cared for. The forum can be a safe place to vent pent-up, unexpressed feelings.

Furthermore, the forum can empower individuals to seek fresh avenues of medical advice, that may be much more helpful than previously. Of course, there may be issues with hasty or ill-conceived communications posted on the forum, and vulnerable people can be very upset by these problems. As with any community, misunderstandings may arise, but may be kept to a minimum by careful rules and moderation.

Overall, this online web resource is a very positive influence in the lives of people who are unable to access the information and support they need elsewhere.

Claudine Goze-Weber presented a **'letter to people without chronic pain'**. She wished to address the invisibility of pain and the lack of awareness most people have about it. She mentioned several important points, paraphrased here:

- 1.□□□ **I'm still human, I'm still me (regardless of the pain and exhaustion)**
- 2.□□□ **Even if I look and sound happy (and I am happy) that doesn't mean I'm 'better'**
- 3.□□□ **Doing something one day might not be possible another day**
- 4.□□□ **'getting out and doing things' isn't necessarily a good thing**
- 5.□□□ **Telling me to try harder isn't helpful**
- 6.□□□ **Please don't suggest a cure! If such a thing existed, I'd know about it by now.**

Claudine concludes: *'I ask you to bear with me and accept me as I am'*.

### **Managing pudendal neuropathy**

Dr Jacques Beco outlined the following lifestyle changes to protect the nerve in pudendal neuropathy :

- Avoid sitting for a long time (use U shaped cushions etc.)
- Avoid biking (cycling)
- Avoid heavy lifting
- Avoid childbirth (especially Caesarean section)
- Treat descending perineum (DPS) by correct positioning on toilet

Symptoms of prolapse, DPS and continence issues can be treated with Kegel's exercises, biofeedback, electrostimulation etc.

Symptoms of pain : may respond to manual therapy such as myofascial trigger point release, trigger point injections/dry needling, cold laser or TENS.

Injection or surgery should be considered only as last resort.

### **The Art of Healing: principles of treatment**

Dr Stephen Bolduc, a fellow at the University Center for Integrative Medicine, talked about a holistic approach to healing.

Firstly, he noted that Tarlov disease brings with it, **'devastating, horrendous symptoms'** which impact on every facet of day to day life. This causes mental and physical harm. Sadly, as he remarked, patients often experience negative medical encounters.

Dr Bolduc suggested that healing involves both intention and presence. It is vital to allow patients to make choices but above all, for the doctor to LISTEN.

Dr Bolduc proposed a holistic approach using Integrative Medicine and including nutritional measures, mind/body techniques such as meditation, herbal medicine and manual medicine (massage etc.)

He concluded by hoping for a future with Centres of Excellence, education for all healthcare practitioners and close links between the different healthcare providers involved in each patient's care.

### **Acute management of arachnoiditis**

Dr Donna Holder (from Texas) recommended the following treatment for blood in the CSF:

1. MRI scan with contrast
2. Bed rest
3. 500mg methylprednisolone intravenously daily for 5 days (similar to spinal shock)
4. Oral anti-inflammatories (NSAIDs) for 3 weeks
5. Gabapentin 400-600mg three times a day for at least 3 weeks
6. Avoid intraspinal procedures

Prof. Aldrete's protocol for acute management of arachnoiditis (within the first 6 months):

1. Methylprednisolone in 0.9% sodium chloride 500mg/24hr for 5 days
2. Gabapentin (or Pregabalin 75mg bd)
3. Amitriptyline/nortriptyline 25mg a day
4. Ketamine 50-75mg/kg iv
5. Lidocaine 3-5mg/kg iv
6. Tramadol +/- paracetamol
7. NSAID (indomethacin/celecoxib)

Prof Aldrete also outlined a different protocol that had been tried on 5 patients: using Keterolac/Diclofenac, Phenytoin and vitamins.

He has published the results of trials of these treatments: Aldrete JA, Ghaly RF 2008 Timing of early treatment of neurological deficits postintervention and operative spinal procedures.

Prof Aldrete also mentioned in his talk that muscle spasm could be effectively treated with an infusion of magnesium sulphate (15mg/kg) or 400mg three times a day orally.

He recommends isometric exercises and a multidisciplinary approach to managing ongoing symptoms.

More details can be found in his recent publication: "**Arachnoiditis: the evidence revealed**"

## Surgical intervention and Spinal cord stimulation

Neurosurgeon Prof Warnke described his intervention using thecaloscopy (an endoscopic procedure). He was at pains to point out that he does not resect scar tissue, he carries out a subarachno-epidurostomy to improve local CSF flow. He is not aiming to influence post-inflammatory changes (scarring), and does not alter morphological (anatomical) changes, bringing about only physiological consequences.

His results show a reduction in pain by 80% at 3 month follow period and 60% up to 72 months.

Dr Mezzadri reported on open and endoscopic treatment of sacral cysts. His team looked at 2 types of cysts: lateral (generally smaller) and medial (generally larger). For lateral cysts, open surgery was performed whereas an endoscopic procedure was used for the medial cysts. The open surgery consisted of a decompressive laminectomy and 'exclusion' of the cyst. In both procedures fibrin glue, muscle or autologous fat were injected into the cyst. Post-operatively patients had an external drain for 4-5 days. Despite complications (fistula and pseudomeningocele) results were encouraging as 5 out of 6 patients became asymptomatic.

Drs Dario and Reverberi presented results of a trial using spinal cord stimulation in arachnoiditis. They implanted firstly a temporary and then permanent device in 4 women with drug resistant failed back syndrome. All patients had bilateral pain and two also had back pain. The average time of having had chronic pain before the implant was 7 and a half years. The average pain score went from 7 down to 3.5 at 18 month follow up.

The authors pointed out that "***arachnoiditis seems to be rather difficult to treat by spinal cord stimulation***" but that in this small trial, the outcome was successful, perhaps because of the multiple source neurostimulator, suggesting that the electrical currents are able to modify the inflammatory component of arachnoiditis.

## Integrative approach

Dr Gerard Mullins, who has arachnoiditis himself, presented a detailed integrative approach to the condition. He particularly spoke on the effects of stress on the body and drivers of inflammatory processes, such as environmental pollution, poor diet and lifestyle issues.

Dr Mullins proposed an Arachnoiditis Restoration Programme:

- Remove (bad bugs, allergens)
- Replace (enzymes)
- Restrain (inflammation)
- Refeed (anti-inflammatory diet)
- Relieve (symptoms)
- Reinoculate (use probiotics)
- Repair (nervine herbs)
- Rebalance (stress management)
- Reconsider alternatives (energy medicine)



He gave detailed accounts of the different aspects of his proposed integrative programme, with particular emphasis on nutritional and herbal strategies to reduce inflammation.

Karen Kovacik presented the protocol that she has been using, under the care of Dr Holsworth who was unfortunately unable to attend the congress. Karen has found the regimen highly beneficial although costly in terms of finances and time.

It comprises intravenous infusions of high dose vitamin C (40-60g) and magnesium chloride (4g): this is designed to ease inflammation. The second phase of the protocol (Patricia Kane protocol) uses intravenous phosphatidylcholine in the first step, followed by leucovorin (10mg) and finally a glutathione push.

Although Dr Holsworth did not present at the congress, the abstract for his talk was included in the booklet all attendees were given. He presented a novel therapeutic approach using oral nattokinase which he suggests corrects impaired fibrinolysis (remodelling of scar tissue by the body). He noted that nattokinase is being investigated in the field of dementia. It is well tolerated, he reports.

Dr Holsworth stated that its use is in conjunction with a multi-disciplined approach identifying areas of concern such as 'leaky gut syndrome' etc and that anti-oxidants are also key in his treatment strategy. He suggests that preliminary findings are encouraging.

## **CONCLUSION**

***“And a man who can make himself merry in the face of these coming disasters that assailed him, as disasters***

***do so many, without grace and favour, is a true hero.”***

***Sebastian Barry, The Secret Scripture.***

Sincerest thanks to Muriel Gendre, President of AARMOR and Claudine Goze-Weber, whose immense hard work and perseverance made the congress a triumph.

### **WHAT THE FUTURE HOLDS:**

The Congress has been a vital first step in a long journey. There are plans for a professionals' meeting in Germany, organised by Professor Jan Warnke, in early 2011. He is also trying to obtain funding for research into arachnoiditis.

On a personal level, numerous friendships were forged during the Congress and I am sure these will thrive and set up a network of support throughout the world.

**Where there is a disaster, there are people trying to recover from it.**

**Where there is suffering, there are people trying to help.**

**Where things go wrong, there are people trying to put them right and trying to make sure they don't happen again.**

**Martin Lewis. Broadcaster**

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**Support Groups**

**[www.theAword.org](http://www.theAword.org) supporting people with arachnoiditis and chronic pain**

**[aracEuropeinformation@yahoogroups](mailto:aracEuropeinformation@yahoogroups)**