



Association AMTAS

Arachnoiditis - Tarlov Cyst Disease - and Syringomyelia

<http://association-amtas.e-monsite.com>

https://youtu.be/R_47uGRuXHY

Let me come to you in order to denounce and highlight the situations of patients when they are affected by Arachnoiditis, Tarlov Cyst Disease and Syringomyelia, diseases affecting the meninges and the nervous system and spinal cord leading to painful manifestations, neurological disorders along with disability. Behind these diseases which are destroying patients' lives, especially when they are abandoned by physicians and scientific research, is hidden a medical scandal about which silence is not acceptable anymore. It's all about invasive practices performed by specialists such as orthopedic surgeons, neurologic surgeons, rheumatologists or interventional radiologists, and so on...

In order to present to you the magnitude of this issue, I'm going to take Arachnoiditis as an example. Most often, Arachnoiditis is of iatrogenic origin, that is to say usually caused by modern medicine. In most of the cases, it is caused by back surgery, lumbar punctures, epidural anesthesia or epidural infiltrations in which the nature of the injected product can affect the meninges called arachnoid (a very profitable medical act especially performed by rheumatologists), invasive tests requiring the injection of toxic contrast products (myelography, discography).

For decades, the promise of a painless delivery was used as an unbeatable argument to perform epidural injections in series and systematically by anesthetists which are not informing their patients about the real risks and potential complications, going along with this medical act, unmarked to an extreme point. Besides, we know that this medical act may be full of consequences but it's very profitable and it represents a business for hospitals. The lack of volunteered information about the dangers of this practice is better understood as it is directly related to profitability. The cost going along with natural delivery and the one of a delivery performed with the help of an epidural injection is clearly giving evidence about that. According to recent studies, painless delivery is leading to deleterious consequences for both mother and baby. These ascertainments are well sheltered from the media. The same can be said for epidural infiltrations most of the time performed by rheumatologists in hospital rooms which aren't a non-sterile environment, and very often by inexperienced interns. It must be noted that this medical act should be performed by interventional radiologists, under a radiological monitoring and not in an assembly-line manner in a unit, directly in the patient's room. The patient suffering from intense pain will be likely to accept without even being informed about the risks, except from a potential headache while in numerous cases, other non - invasive alternatives can be offered. Medical literature has shown the presence of very severe complications, secondary to this very risky act although it's presented as a simple puncture in the back. Once again, profitability wins over the patient's protection and the same goes for lumbar punctures. Arachnoiditis' symptoms can become obvious after some months as well as ten years from the causing medical act. No European or French serious study is completed which enables physicians to overlook the

cause to effect relationship and even worse, they are adopting a behavior characterized by denial regarding this inflammatory and neurodegenerative complication and towards the symptoms it is causing, going as far as destroying the person's affected by this disease family, social and professional life. When painful symptoms occur going along with neurological disorders, patients are referred to inappropriate physicians or specialists, are lost in a medical desert, deprived of serious and tailored to their needs management and then end up as being rejected by the whole set of medical professionals, being thus the victims of discrimination.

This rejection consists among other things in considering the individual affected by this disease as presenting symptoms caused by the way their brains are working. Where is the Hippocratic Oath which advocates honesty, devotion and care for everybody? It seems now that it is merely an illusion. We are disturbing patients which are willingly placed in psychiatric units in order to be gotten rid off cowardly. It is not practicable in such a denial spirit to wait for a management from medical professionals in order to relieve symptoms among which atrocious pains in every way possible nowadays. Medical publications (often published in English as it should be done) are however available on the Internet, explicit enough about the diseases manifestations along with about the dangers of specific medical acts on English as it should be done but French doctors are not willing to inform themselves seriously and are not willing either to collaborate with foreign doctors and researchers, really studying these diseases which are neuro degenerative, genetic or even caused by surgical traumas. In medicine and surgery, we should when it's possible to be as less invasive as we possibly could and especially, patients should be clearly informed about risks and benefits in a transparent manner. Hospitals have lost their core mission and are becoming firms with a lucrative aim to the detriment of patients for which physicians are using unscrupulously medical acts which can destroy human lives. How long will we have to keep our mouths shut and continue to be the victims of this lucrative business? How many patients will have to deal with the consequences of this health policy? Business to the detriment of humanity is no longer acceptable. Should we still increase the number of victims from this health process whereas all the physicians and specialists are well aware of the risks of these medical procedures? Business to the detriment of mankind is no longer acceptable. Arachnoiditis is classified as a rare disease on Orphanet Website. Besides we know that affected patients are numerous but most of the time, they are not diagnosed. Radiologists are under pressure and are less and less keen to name the disease in their reports as it is also the case for Tarlov' cysts disease : it seems like we are facing a beautiful omerta here. Arachnoiditis is first of all a serious complication directly related to invasive surgeries and medical acts performed on the spine. An eminent professor in Florida talks about "silent epidemics", while in France and other European countries, it is classified in a "rare diseases" box which is easier in order not to confront and deal with the consequences of acts committed by medical professionals and not to commit their responsibility too much. Too many patients are seeing their lives collapsing simply to feed this medical business and especially in order for these medical professionals (a supportive and hermetic corporation),partly corrupted and having too closed links with pharmaceutical labs to carry on acting like that without even being disputed and with a feeling of strong powerfulness.

It's not possible for us to talk about "rare diseases" anymore but more accurately about a destructive process, leading to the onset of those diseases and causing irreversible lesions and after effects, extremely painful, mutilating lesions on the spine caused by the so called modern medicine. How can invasive practices, tending to generalize these diseases can remain unveiled and labeled as "rare diseases" while we know that cases listed in foreign countries are more and more numerous (see Dr Tennant and Pr Aldrete).This medical system, reducing the patient to goods is not acceptable anymore. Our patients' situation is very worrying and is affecting the rights to good health and well-being.

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