European Tarlov
Cyst Alliance ©
European Network for Information
about Tarlov Cyst Disease

My name is Glenda Soper and I am writing to ask if you could kindly include tarlov cysts disease as part of your plan of choice for rare and orphan diseases.
Without help support and intervention this is a debilitating and severe unrelenting spinal condition which has a big impact on mobility, the ability to work and to socialise. These can lead to isolation and chronic severe spinal pain.

Sufferers often need help with daily living tasks in and around the home and help with personal care and dressing lower half in some cases. This condition needs further research and education of the medical community and general public. we have a support group. Tarlov Talk and Tarlov Europe but desperately need help to bring this condition to light. I am also a sufferer and you will find my personal story enclosed. I do hope you will give this serious consideration.

5% of the population have Tarlov cysts and one in five can become symptomatic due to trauma, fall, car accident or childbirth as this increases the csf within the cyst causing it to increase in size and compress nerves inside and outside the cysts.

my Address is:-

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I have included a s.a.e and eagerly await your response.
Thank you very much for your time with the enclosed.
Yours sincerely
G.M. Soper

Tarlov cyst sufferer

My name is Claudine Goze-Weber, but I am speaking for all Tarlov's patients in Europe and the world.

In 2001, I discovered that I have a rare disease: sacral meningeal cysts, more commonly called Tarlov's cysts.

The reason I learned of it is that, because of a fall in November 2001, severe pain developed due to this pre-existing health problem. This pathological stage brought on by the fall induced neuropathic pain by compression of the sacral nerve roots.

This disease can become symptomatic at any age, even in children. One of the youngest "Tarlovians" was 16 months old when diagnosed. At this point, nobody knows what really makes the life of a patient go from a quasi-normal to a world of intractable pain

It seems that there is a lack of information and awareness of doctors about this condition.

Through the internet, I have contacted people with Tarlov's cysts everywhere in the world. My condition can no longer be helped, having gone through an experimental and failed surgery that led to more problems. So, I let my pain push me to find help for other people and try to help them avoid making the same mistake I did.

I studied all aspects of this pathology with the few scientists, mostly neurosurgeons, who were willing to "waste" their time on the subject. I am personally in touch with Doctor Daniel Maitrot in France, and also with Doctor Long of Johns Hopkins Hospital in Baltimore through other patients. I am also a member of the American Tarlovcysts Foundation for this rare disease.

I have created, with other people in Europe who are also suffering from sacral meningeal cysts, websites providing information in French, English, Italian, and Spanish, and a German site is in preparation.

To summarize the issues surrounding this disease:

This health condition is a type of cyst of the sacral meninges, which affects the sacral nerve roots. According to researchers, it appears that this defect occurs during gestation, when the neural tube is formed.

Tarlov's cysts are sacs in the arachnoid membrane of the sacral region. Unlike most cysts, they are filled with cerebrospinal fluid. The bone of the sacrum itself is often eroded and very thin.

Because this problem is meningeal, neurological, and osseous, it is extremely painful and results in severe disabilities.

Nerve roots are trapped and compressed inside Tarlov's cysts, causing neuralgic pain and neurological disabilities. Problems are not limited to the level of the sacrum, but also extend to the legs, often resulting in leg weakness, difficulty or impossibility in walking, urinary and intestinal disorders, and other cramps and spasms in the pelvis.

Victims often suffer intense headaches, sight, and balance problems, probably resulting from disorders of the spinal fluid circulation. This pain can be as severe as that of meningitis. The meninges, of course, are exquisitely sensitive, and pain can be felt throughout the central nervous system. Severe pain is felt as being deep inside one or both legs, the sacral region, and the lower back. No position gives relief and frequently none of the currently used drugs, including morphine, can help.

Other sensation symptoms include hypoesthesia, hyperesthesia, allodynie, and any others that can result from damaged and malfunctioning nerve roots. Disabilities resulting from both the pain and nerve damage include limitations in sitting and walking, even complete loss of the ability to walk. Muscles become atrophied. Patients also suffer from lack of sleep due to the intensity of the pain.

Patients with Tarlov's cysts face:

Physical pain: The burning and wrenching neurological pain is unbearable and unrelenting.
Lack of diagnosis: Because so few doctors are familiar with Tarlov's cysts, the disease often goes undiagnosed, even when it shows on MRIs. Often, even when diagnosed, its effects are believed by physicians to be nonexistent. This fact, added to the others, has severe consequences. Patients are often told that their problems are psychosomatic, and—as happened to me—may even be told that they require treatment in a mental institution.
Psychological pain: The 24 hours a day, 7 days a week pain has major repercussions on the patient's mood. Because these pains are not visible and often not recognized by the professionals, because patients are told they're suffering from psychosomatic disorders and often called hysterical, family and friends do not understand and cannot provide the needed support. The psychological pain related to isolation and loneliness is as heavy and unbearable as the physical pain.
Economic costs: The repercussions on the patient's social and economic life are enormous. As must be obvious from the prior descriptions, losing one's job is common. Aside from the personal psychological costs, society must pay for the lost productivity and the need to provide medical and social benefits.
Social and personal costs: Tarlov's cyst patients often suffer from social systems that have little recognition of this disease. As a result, the patient is suspected of unfounded requests to stop working. Disability systems then refuse to provide their benefits, thus leaving the patients unable to work and without any support.
Often, people with Tarlov's cysts who attempt to continue working, but are limited because of the pain or disability, are confronted with the problem of employers who refuse to make it possible by insisting they do things that they cannot accomplish. In the context of physical pain and the deep feeling of isolation and loneliness, to then be ignored by one's employer and the health and social systems, the precariousness of one's position quickly leads to depression, becoming the focus of everyday life. Hope disappears.
Depriving people of hope is to deprive them of their reason for living.
Thank you for reading and listening.

Respectfully and gratefully yours,
Claudine GOZE-WEBER

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http://tarlov-arac.populus.ch/ (France)
http://tarlovdisease.populus.ch/(English)
http://cistiditarlov.populus.ch/ (Italian)
http://quistesdetarlov.populus.ch/ (Spanish)
http://torbieletarlova.populus.ch/(Poland)

http://www.tarlovcystfoundation.org/ (USA)

Tarlov Cyst Sufferer

My name is Glenda ,
Here is my op story.

My symptoms 1st began after a nasty fall and lifting heavy stuff all in 1 week. I had backache since age 16.When having a job which involved lots of lifting. With some surgeries recovery can take a couple of years. My 1st decompression only wasn't successful. This was because my cyst was 6 -7cms lieing down.[communicating type-filled more when stood up on myelogram] and the usual amount of decompression was not enough for such a large cyst. The bone was still causing pressure on the cyst. I also had S1 foramina stenosis bilaterally[both sides]. This wasn't seen at my 1st surgery because they didn't expose the bone that far back [the foramina are the holes on each side of the sacrum where the sacral nerve comes out from.] however every other patient I am led to believe are symptom free.

2 I know of personally aren't completely symptom free but a lot better then before surgery and our cysts were termed ARACHNOIDS which is a variation of a TC but harder to treat. One was a physiotherapist who was forced to give up her own practice. After surgery she managed to resume her practice part time. The other lady is also a member of Tarlov Talk. and Europe. Like myself she has gone on to have a baby. I have had 2. So we are a lot better then before surgery .On my 2nd and 3rd ops I had more extensive decompressions also excisions that were partly successful. 2nd op decreased cyst from 6-7cms 3cms and 3rd and most successful op decreased it to 1.5cms. The bladder and bowel symptoms disappeared after 6-9 months and the sacral leg pain that swapped from side to side went away after 2 years. My last surgery was in 1990 and my cyst hasn't increased in size. So I am a lot better I am not bed ridden like before ops and in-between surgeries and I can now sit for short periods .My mobility is limited so is my time up due to radical decompression[roof of sacrum removed]fromL5/S1-Coccyx.I prefer this to the constant pain I had before as don't suffer with nerve pain in my legs unless I have pulled the scar tissue involving nerves.
Last 18 mths or so get parestetias at ovulation and period Or 1st thing in the morning then gone for rest of day.I think this is due to micro blood flow circulation from scar tissue and womb pressure ,adhesions cesarian stuck to blaader and possibility of endometriosis.

I hope this helps. Best wishes

Glenda.
Glenda Soper

Tarlov Cyst sufferer

LETTER TO FAMILY & FRIENDS

Dear Family and Friends,

This letter was written in hopes of improved understanding of those who live with symptomatic Tarlov cysts and the chronic pain, nerve damage, and life altering changes they cause.

Having cysts on my spinal nerve roots and the resulting nerve damage causes chronic pain and means many things in my life change, and a lot of them are invisible. Most people do not understand about relentless, intractable pain and its effects, and of those that think they know, many are actually misinformed. In the spirit of informing those who wish to understand, these are the things that I would like you to understand about me and my medical diagnosis, Tarlov cysts.

Please understand that living with this medical condition doesn't mean that I am not still trying to live a "normal" life. However, I spend most of my days and nights in considerable pain and exhaustion; sometimes I probably don't seem like much fun to be with, but I'm still me........ stuck inside this changed body. There are things that I can no longer do, and I have had to accept that. I worry about how the changes in me are affecting you. I care very much about my family and my friends, and I'd still like to hear you talk about your life, your family, and your activities. I like to talk about things other than me and my medical condition and pain. I still have the same interests I have always had; there are just some of them I can no longer actively pursue. I am grateful, by the way, for the things I can still do, my faith in God, and the blessing of your support, love and friendship.

Please understand the difference between "happy" and "healthy". When you've got the flu, you probably feel miserable with it, but in a week or two you are back to normal. I've been living with this diagnosis and its symptoms for years; I can't be miserable all the time. In fact, I work hard at not being miserable. So, if you're talking to me and I sound happy, it means I'm happy. That's all. It doesn't mean that I'm not in pain, or not extremely fatigued, or that I'm "getting better". Please don't say, "Oh, you're sounding good!" or "But, you look so good", as if nothing could possibly be wrong. When I am around you and others, I try to smile, laugh, and enjoy being with you. I am merely coping. I am happy to be with my friends and family and trying to look normal and act normal; it does not mean that I am not in pain or that I have had a miraculous recovery.

Please understand that being able to sit, stand , walk, or be sociable for 15 minutes doesn't necessarily mean that I can sit, stand , walk, or be sociable for thirty minutes, or an hour. Just because I managed to sit, stand , walk for thirty minutes at a time yesterday doesn't mean that I can do the same today. With this medical condition, it gets more confusing everyday. It can be like a yo-yo. I never know from day to day, how I am going to feel when I wake up, and how painful the day will become; in most cases, I never know from hour to hour. That is one of the hardest and most frustrating components of living with Tarlov cysts and chronic pain. It sure makes planning ahead difficult, and it means I have had to adapt to an altered life style.

Please understand that chronic pain is variable. It's quite possible that one day I am able to take a walk, go out to lunch with you, go shopping , or to church, although when I get home or the next day I'll have trouble walking to the next room. Please don't be confused by saying or thinking, "But, you did it before!" or "Oh, come on, I know you can do this!" If you want me to do something, then ask if I can. I may need to cancel a previous commitment at the last minute. If this happens, please do not take it personally. If you are able, please try to remember how very lucky you are to be physically able to do the things that you can do. I have to re-prioritize my plans and activities constantly, because of the pain and other symptoms that persist. I am still learning each day to cope with what I can no longer do, and to remain very thankful for what I can do.

Please understand that "getting out and doing things" does not always or necessarily make me feel better, and can often make me seriously worse. I really try to be as active and involved in activities as I possibly can, as far as the pain and symptoms allow. If I was capable of doing something that would take it away all of the time, don't you know that I would? You know me and know how my life was before these Tarlov cysts and resulting symptoms began and have continued. Obviously, chronic pain can deal with the whole body, or be localized to specific areas. Sometimes participating in a single activity for a short or a long period of time can cause more symptoms and an increase in physical pain. The recovery time from doing something I should not do, or longer than I should do it, is significant. I call it ODI (overdoing it) and I pay for it dearly .You can't always read the pain on my face or in my body language. The pain is not caused by depression. The sadness and sometimes irritability that you might hear in my voice (even though I try hard to hide it) is from the pain and adjustments I have had to make in my life to go on, and it is due to the changes such as the loss of my job/career, my inability to jump in the car whenever I want to run errands, see a movie, go to a restaurant, visit friends, shop, clean my house, work in my garden, etc. as I did previously.

Please understand that if I say I have to sit down or lie down now, that probably means that I have to do it right now; it can't be put off or forgotten just because I'm somewhere else, or am in the middle of doing something. I have had to lie down in the floor in my doctor's office when I had to wait too long, and could no longer sit or stand. Chronic pain does not forgive, nor does it wait for anyone.

You may have wondered why I don't just take something stronger for the pain. I have tried many different medications, as well as surgery which failed and caused more nerve damage , complications, and more pain. I have been made worse, not better, due to side effects or allergic reactions from the medications. There is worldwide networking (both on and off the Internet) between people with Tarlov cysts. If something always worked to relieve the symptoms and get rid of the cysts, we would know. These symptomatic cysts on the spinal cord nerves are rare, and are not related to more commonly understood problems, such as herniated or ruptured discs. Currently, there is only a handful of courageous Neurosurgeons and Interventional Neuroradiologists in the world who are seeing the majority of patients with this rare disorder and are willing to attempt treatment. Currently, the treatment outcomes are not indicating a high percentage of complete cures.

If I seem touchy, irritable, or distant occasionally, it is probably because I am. It's not how I try to be. As a matter of fact, I try very hard to look and act normal. I hope you will try to understand. I have been, and am still, going through a lot of change. Chronic pain is hard to understand unless you have had it. It wreaks havoc on the body and the mind. It is exhausting and exasperating. Almost all the time, I know that I am doing my best to cope with this, and to live my life to the best of my ability. I ask you to bear with me, and accept me as I am, though changed from the way you knew me before TCs. I know that you cannot literally understand my situation unless you have been in my shoes, but as much as is possible, I am asking you to try to be understanding in general.

In many ways I depend on you. I need you to call or visit me when I cannot go out. If you live with me, sometimes I need you to help me with the shopping, cooking, cleaning, gardening. You know me well enough to know it is very difficult for me to ask for help. I may need you to sometimes take me to appointments, or go shopping with me. You are my link to the normalcy of life. You can help me to keep in touch with the parts of life that I miss so much. I know that I have asked for a lot of understanding from you, and I do thank you for listening to my innermost thoughts on paper. It really does mean a lot to me that you care. My head and heart are still the same; it is my body that has changed, and my life as I knew it before Tarlov cysts has changed. One of my most heartbreaking moments was when my 9 month old grandson, with a big smile on his face, reached his arms out to me to pick him up and hold him, and I could not lift him. That was over 6 years ago and my granddaughter is now 9 months old; I am concerned that she will never know her grandmother ("Gammy") as an energetic and strong woman. These may seem like little things, but it is sometimes those little things that make you aware of the changes Tarlov cysts have caused. Thank you for trying to understand what I myself do not completely understand. I appreciate your love, concern and prayers. This new journey of learning to live with this medical condition has blessed me in many ways. I have met many new friends along the way and find myself surrounded by God's blessings in my life each day.

My career was spent as a nurse and healthcare/medical educator. I plan to contribute my time and energy to the best of my ability with God's new direction for me in my life. I have been and will continue to focus on the future growth and operations of a Foundation, whose purpose is to promote research and education for the medical community and the public, for improved understanding and treatment for Tarlov cysts. The Tarlov Cyst Disease Foundation's vision is of a future in which Tarlov Cyst Disease is well understood, accurately diagnosed, and easily treated, so that those afflicted should not suffer needlessly. We hope to make the path a little easier for others with this rare diagnosis; we hope our efforts will bring about a cure in the future.

God bless you for caring,

Reta

Reta Honey Hiers, R.N., C., President
Tarlov Cyst Disease Foundation

P.S. If you are a TC patient, please feel free to print this letter and share it as is, or edit it to make it
your own to share .

EU Questions :

Question 1: Is the current EU definition of a rare disease satisfactory?

(for example) codification: **Better codification and classification of RD**: The EU should cooperate closely with WHO
in the process of revising the existing ICD (International Classification of Diseases) in order to ensure that RD can be adequately coded to be traceable in all health information systems. This requires the support of a working group on Classification and Codification of RD, acting as Advisory Working Group to the WHO in the ICD revision process20. An active cooperation of the EU Statistical Programme should also be necessary as soon as the new ICD-11 is available in order to ensure the use of the new ICD version including new codes for RD in the death certificates and in the hospital discharges tabulation systems in all MS. A similar effort should be made to ensure proper coding of RD in the SnowMed and in the MedDRA coding systems.

Question2: Do you agree that there is a pressing need to improve coding and classification in this area?

(for example) **Establishment of an inventory of RD**: among the causes of neglecting the issue of RD is
the ignorance of which diseases are rare. It is necessary to provide the community with an accurate inventory of RD, regularly updated, classified by medical specialty, by prevalence, by mechanism, by aetiology, so as to maximise awareness and to provide documentary support to research and data storage in general. The European Commission should provide financial support for this activity through the Public Health Programme.

Question 3: Can a European inventory of rare diseases help your national/regional system to better deal with RD?

Dissemination of appropriate information
Support to information networks
Development of national/regional centres of reference and establish EU reference Networks

Question 4: Should the European Reference Networks privilege the transfer of knowledge? The mobility of patients? Both? How?

Development of e-Health in the field of RD

Question 5: Should on-line and electronic tools be implemented in this area?

Availability and accessibility of accurate diagnostic tests, including genetic tests

Question 6: What can be done to further improve access to quality testing for RD?

Evaluation of population screening (including neonatal screening) strategies for RD:

Question 7: Do you see a major need in having an EU level assessment of potential population screening for RD?

Primary preventive measures when possible

Best practices on RD care:

Equal access to orphan drugs:

Question 8: Do you envisage the solution to the orphan drugs accessibility problem on a national scale or on an EU scale?

Orphan Medical devices and orphan diagnostics:

Question 9: Should the EU have an orphan regulation on medical devices and diagnostics?

Health Technology Assessment of Orphan Drugs:

Coordinated compassionate use programme:

Specialised social services

Question 10: What kind of specialised social and educational services for RD patients and their families should be recommended at EU level and at national level?

To accelerate research and developments in the field of RD and OD

Question 11: What model of governance and of funding scheme would be appropriate for registries, databases and biobanks?

Question 12: How do you see the role of partners (industry and charities) in an EU action on rare diseases? What model would be the most appropriate?

Question 13: Do you agree with the idea of having action plans? If yes should it be at national or regional level in your country?

Question 14: Do you consider it necessary to establish a new European Agency on RD and to launch a feasibility study in 2009?

Responses to this consultation, focussed around the specific questions identified in the text above, should be sent to the Commission by 14 February 2008, by email to

sanco-rarediseasesconsultation@ec.europa.eu, or by post to:
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All contributions received will be published, unless specifically indicated otherwise.
Following
this consultation, the Commission intends to bring forward appropriate proposals in 2008.