

We are here for you!



ASSOCIATION QUÉBÉCOISE
DE LA DOULEUR CHRONIQUE

A Message from the President of AQDC

In 2004, Association québécoise de la douleur chronique (AQDC) was founded with the mission of improving the lives of Quebecers suffering from chronic pain and breaking their isolation. From the start we positioned ourselves as an association of patients for patients. Our goal is not to find a complete or miraculous cure, but simply to find some relief so that our lives have meaning and we can live in harmony with the world.

Just as we recommend that those suffering from chronic pain take an active role in their own care and related decisions, AQDC is working across the board to defend members' interests. Not only do we seek assistance from the government, but we also want to be part of the solution.

To this end, the Association has a seat at Table sectorielle en douleur chronique of Ministère de la Santé et des Services sociaux (MSSS). AQDC representation at the table ensures that people

with chronic pain stay at the center of the decision-making process. The work of Table sectorielle has led to the creation of centers specializing in the management of chronic pain that are tied into one of the four Réseaux universitaires intégrés de santé (RUIS): Montreal, McGill, Sherbrooke, and Quebec City. The main responsibility of these centers is to improve chronic pain management and to ensure the quality and continuity of first, second, and third line care. They also have a teaching role (for doctors and nurses, etc.) and a research mission.

Each year, the Association awards three to five \$5,000 scholarships to healthcare professionals who wish to broaden their knowledge in the field of chronic pain. Since the inception of this program, five years ago, a total of 16 scholarships have been awarded.

In addition, some fifteen people from AQDC were trained last year by McGill University to conduct a workshop on self-management of chronic pain. Since then, approximately 100 people have attended this free six-week program designed for chronic pain patients and

their families. By the end of 2012, this workshop will be available in most Quebec regions.

We plan to set up a 1-800 hotline to keep patients informed of available resources. This pilot project could lead to a new, complementary service on our website, which is already packed with information on chronic pain. With its regularly updated documentation center and video library, www.douleurchronique.org is a veritable gold mine of information for patients seeking advice on how to better manage their pain, or for anyone wanting to learn more about this occasionally misunderstood disease.

Raising awareness among the public and politicians is another main concern for AQDC. Besides the current special report, we participate in numerous public seminars throughout Quebec on various issues related to chronic pain. In addition, we just created a Facebook page to allow members of this social network to discuss chronic pain.

Seven years after its creation, AQDC continues to pursue its mission with the same determination. We now have about 4,500 members and



Jacques Laliberté, president, AQDC

numerous friends. I invite all Quebecers to embrace our cause by joining our Association for free. Membership in AQDC is not limited to people with chronic pain. People who live with pain sufferers or who are simply interested in chronic pain can also join. The bigger our membership, the more influence we will have to convince policymakers to accord the treatment of chronic pain its fair share of resources. I hope this report will convince you of the value of your support.

Thank you!



Did you know that...

The World Health Organization (WHO) has recognized chronic pain as a disease since 2004. This scourge affects 24% of Quebec women and 20% of Quebec men, or 1.5 million people. In Canada, it is estimated that costs generated by the utilisation of health care resources and the productivity loss exceed 6 billion dollars per year.

In the 18-55 age group in the United States, back pain alone generates more disability and is more costly than cancer, cardiovascular disease, strokes and AIDS combined. (Cousins et al, 1995/Loeser, 1999.)



Glossary of Chronic Pain Terms

AQDC presents an easy-reference glossary with definitions of the most common medical terms related to chronic pain and other conditions, the majority of them painful. The electronic version of this glossary is updated regularly on the web site (www.chronicpainquebec.org)

A **SICKLE CELL ANEMIA**

An inherited blood disorder characterized by a change in the shape and rigidity of red blood cells that results in the obstruction of blood flow.

ANTICONVULSANT

A drug used to prevent, reduce the frequency and severity of, or arrest epileptic seizures.

ANTISPASMODIC

A drug used to reduce muscle stiffness associated with certain neurological diseases.

C **CO-ANALGESIC**

A drug without analgesic properties in the strict pharmacological sense but that is very effective at relieving certain types of pain.

D **PHANTOM PAIN**

Painful sensations perceived in an amputated limb.

NEUROPATHIC PAIN

Pain which, because of nervous system damage, is experienced after a stimulus that would ordinarily cause little or no pain; or pain that arises spontaneously, i.e., in the absence of stimulation.

E **ENDORPHINS**

Substances naturally produced in the brain that inhibit incoming pain messages. They resemble morphine and can be just as potent.

ENKEPHALINS

Substances naturally produced in the brain that inhibit incoming pain messages. They resemble morphine and can be just as potent.

EPIDEMIOLOGY

The study of the various factors involved in the development and progression of diseases.

F **FIBROMYALGIA**

A disorder characterized by chronic muscular pain (myalgia) that is either diffuse or focused at "tender points" and is accompanied by fatigue, insomnia, and in certain cases depression.

L **LOW BACK PAIN**

Pain in the lumbar region of the back (the concave area above the buttocks).

M **INFLAMMATORY DISEASES OF THE INTESTINES**

Diseases of the digestive tract (from mouth to anus) that cause intestinal inflammation and abscesses prone to bleeding. This term groups together two diseases: Crohn's disease and ulcerative colitis.

N **NEUROSTIMULATION**

Neurostimulation utilizes a small implant placed under the skin via an incision. The implant sends mild, precisely controlled electrical pulses—felt as pleasant tingling sensations—to the nervous system. These electrical pulses are delivered through an electrode (a special medical wire) that is also implanted by incision. The electrical pulses prevent pain signals from reaching the brain, thus relieving pain. Because neurostimulation works in the zone where pain signals travel, the electrical pulses can be directed to cover specific areas where pain is felt. Neurostimulation does not involve the use of drugs, so there are few of the side effects that often accompany other treatments.

NEUROTRANSMITTER

A substance released by nerve endings that can relay messages from one cell to another to produce a biological effect.

TRIGEMINAL NEURALGIA

Sharp pain felt along the length of the trigeminal nerve or on one side of the face, i.e., the jaw and cheek, the temple near the ears, and around the eye.

P **PREVALENCE**

The number of cases of a disease in a given population.

PROGNOSIS

Assessment of a disease's progression and outcome.

S **MULTIPLE SCLEROSIS**

A nervous system disease that attacks patches of myelin, the protective sheath that covers the nerve fibers in the brain and spinal cord. The result is the disruption or blocking of signals that travel along the nerves.

COMPLEX REGIONAL PAIN SYNDROME

An unpredictable complication that can arise after any sort of trauma to a part of the body. It is characterized by intense diffuse pain that gets worse at the slightest stimulation (hot, cold, emotions, movement), stiffness, and changes in the skin (swelling, color, temperature).

Z **SHINGLES**

An infectious disease caused by reactivation of the varicella zoster virus. It is characterized by the appearance of blisters over an area of skin and by acute pain.



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Support Groups Finally Come to Quebec City

“Support groups have long been a priority of Association québécoise de la douleur chronique (AQDC),” notes Ms. Line Brochu, vice president of the Association and its representative on the Consortium Coordinating Committee of Réseau universitaire intégré en santé (RUIS). “It was during one of these meetings that I was offered a space for a support group within CHA (at Hôpital de l’Enfant-Jésus) in Quebec City,” she explains. “It’s a pilot project expected to

subsequently start up in other parts of Quebec.”

The support groups began October 20 with a presentation by AQDC describing the workshops and support group program. They now meet regularly, every second Thursday of the month. “Support groups are intended to inform and help chronic pain sufferers and their families,” added Ms. Brochu. “We want them to be educational, not depressing.”

Every session starts with a lecture given by an anesthesiologist, neurosurgeon, pharmacist, or other expert who can answer questions from people with chronic pain. Afterwards, the

AQDC representative shows videos, hands out documents, and updates people on the most recent discoveries and other news that may provide relief to chronic pain sufferers.

Workshops

The workshops are part of a chronic pain management program that will be available throughout the province. The workshops were developed at Stanford University and are now offered in nine languages worldwide. The workshops are led by volunteers, themselves suffering from a chronic disease, who have been trained and certified to administer these sessions. More than two decades of research

demonstrate that these workshops can make a real difference. For more information, visit www.mytoolbox.mcgill.ca/en.

Ms. Brochu and Ms. Linda-Marie Blais will administer this training in Quebec City and Eastern Quebec. It will be offered in Western Quebec as well.

Accomplishments of the AQDC in 2011

- Completely rebuilt the Internet site and created a Facebook page.
- Participated for the third consecutive year in the Salon Équilibre Santé Forme in January 2011.
- Participated in the Salon Prendre sa place at the Montreal Complexe Desjardins in May 2011.
- The president of the AQDC served as a panelist at the annual congress of the Conseil de la protection des malades (Council for the protection of the ill) on June 19 and 20 in Saint-Hyacinthe.
- Organized French sessions for the pain self-management program.
- Translated manuals in French for the pain self-management program.



Mr. Jean-Claude Lamouche, founding member of the AQDC, and Ms. Linda Marie Blais, volunteer.

- The AQDC held a kiosk as part of the Awareness days organized by the ACCORD program. These days were held on October 31 and November 1st at the Complexe Desjardins, a week before the Quebec Chronic Pain Week.
- Created a self-help group in Quebec City.
- Participated actively in the meetings held by the Réseaux universitaires intégrés de santé (Integrated health university networks)

Upcoming activities in 2012

- Will act as a partner of the Canadian Pain Summit on April 24, 2012 – reserved for health care professionals only.
- Will coordinate a pilot project for a toll free 1-800 helpline.
- Will take part in public shows.
- For further information, consult the www.chronicpain.org

Ms. Line Brochu, vice-president and founding member of the AQDC, Dr. Yves Bolduc, Quebec Minister of Health and Social Services, and Mr. Jacques Laliberté, president and founding member of the AQDC.

Treating Chronic Pain Is a Team Effort

Ideally the treatment of chronic pain (CP) calls for a multidisciplinary approach comprising medical (doctors and nurses), psychological, and rehabilitation healthcare professionals. "It is a team effort and everyone must work together to address the patient's specific needs" says Aline Boulanger, Director of the Pain Clinic at CHUM and an instructor at Université de Montréal, in an interview.

She points out, for example, the importance of psychological counseling given that an estimated 30 to 60% of chronic pain patients fall victim to depression directly related to their suffering, and half have suicidal thoughts at one time or another. Other patients require

rehabilitation treatment to regain physical fitness.

As for medical treatment, there are several possible strategies. The best known, according to this specialist, involves the use of drugs and cortisone injections. There are also state-of-the-art treatments like pumps and subcutaneous neurostimulator implants. Of course, surgery is an option used in pain relief, "but we operate less and less because it doesn't necessarily bring about a cure."

Light at the End of the Tunnel

Dr. Boulanger emphasizes that when pain is treated early and aggressively there is less chance it will become chronic, and patients will be able to recover. In this vein, she laments the long waiting times at the pain clinic, especially for those in need of all services—adding in the same breath that she sees impro-

vements ahead with a plan to create a network more accessible to all patients.

She points to other positive indicators on the horizon: growing government and public awareness of the social and economic implications of chronic pain and its impact on the family; and a redesigned training curriculum for future doctors at University of Montreal's Faculty of Medicine and probably at other institutions as well, which will educate them on the diagnosis and treatment of pain. Finally, inspired by self-management programs, CHUM's educational program offers six classes for patients on learning how to manage pain.

When people are better informed they tend to seek out professional advice and take steps to counter pain. "It's important to stay hopeful and not sequester yourself at home; otherwise discouragement can set in quickly."



Dr. Aline Boulanger

Get out of your shell!

If you are suffering from chronic pain, you need to act without delay to get help to take control of your pain, recommends anaesthesiologist Aline Boulanger, Director of the Pain Clinic at CHUM and teacher at the Université de Montréal. This approach is based on at least four fundamental rules: 1) break your isolation, 2) end the silence surrounding your situation, 3) take care of yourself, and 4) make the move to consult a doctor or health professional.

We all know that doctors are very busy and that their time is valuable. It is therefore very important to carefully prepare for the interview you will have with the general practitioner or other health professional.

You should be able to explain your problem and ask any questions about it when you talk to your doctor. In the weeks or even months before your interview be sure to write down the symptoms you feel and their frequency, time

and the circumstances when they appear. Be specific; don't just say that it hurts.

Try to determine, for example, if the pain is sharp, dull, throbbing, cramping, tingling, burning... and where, if it is sensitive to the touch and the intensity of this suffering. You may be asked to speak of a pain scale, that is, to quantify the intensity of your pain on a scale of 1 to 10. Remember that aches and pains are not the same for everyone.

Write down specific questions that you want to ask the doctor, putting them in an order of priority. List any medications (prescription or over the counter), vitamins, natural or homeopathic products that you take and the doses. Don't be afraid to tell the whole truth, remembering that a doctor has already heard it all.

When the long awaited moment arrives, don't forget your Medicare card or your medical record, if you have one (or your notes, of course). Ask for leaflets or brochures for additional information if necessary, or even for how to get them. Consult the website for the Association québécoise de la douleur chronique—Quebec Association for Chronic Pain

(www.chronicpainquebec.org) where you will find a wealth of most relevant and reassuring information tools.

Once back home, make sure to follow the recommendations and instructions received and remember that you are the person best placed to ensure your

own quality of life. The most important thing is to get out your shell!



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CHRONIC PAIN: MYTHS AND REALITIES

MYTH: Managing pain with drugs is standard practice for everyone.

REALITY: Every individual reacts differently. Pain management and treatment vary from one person to the next.

MYTH: Patients who use opioids to control their pain become addicted.

REALITY: Tolerance and addiction to opioids are rare when these drugs are prescribed over a short period.

MYTH: Pain drugs must be prescribed only when pain occurs.

REALITY: It's easier to manage pain when these drugs are taken on an ongoing basis rather than only when needed.

MYTH: Uncontrolled pain is inevitable during the progression of many serious diseases like cancer.

REALITY: Pain is not necessarily an inevitable part of serious diseases and can be controlled with drugs and other therapies.

MYTH: Enduring pain develops strength and character.

REALITY: Non-treated pain depresses the immune system and should be treated promptly.

MYTH: Physicians must choose between treating the disease and treating the pain.

REALITY: False. Pain should be treated promptly so the body can marshal its resources to combat the disease.

MYTH: When pain increases, this means the disease is worsening.

REALITY: It is true that pain can signal the presence of disease. But it is also true that pain can come and go without reason.

MYTH: The purpose of managing chronic pain is to keep drug doses as low as possible.

REALITY: The real goal is to bring comfort and a better quality of life to those suffering from chronic pain.

MYTH: Because of the risk of addiction, opioids must be prescribed only for the terminally ill.

REALITY: People have exaggerated notions about addiction to opioids. There is a distinction between physical and psychological addiction.

MYTH: Asking patients to assess their pain on a scale from 1 to 10 is inadequate.

REALITY: This assessment of pain by the patient helps define its severity and improve pain management.

MYTH: People with chronic pain will ask for medication only when needed.

REALITY: Many people with chronic pain do not ask for medication, and when they do it is often not soon enough to establish quick and adequate control.

MYTH: Complaining about your pain can distract your physician from treating the disease.

REALITY: Treating pain is as important as treating the disease. Let your doctor know.

MYTH: Wait as long as possible before taking a drug in order to increase your tolerance to pain.

REALITY: Waiting too long to treat pain can reduce your mobility, depress your appetite, disturb your sleep, and in sum total be very harmful to you.

MYTH: Injecting an analgesic is more effective than taking one in pill form.

REALITY: An injected analgesic is faster acting than a pill. When precautions are taken, the pill can be just as effective in relieving pain as the injection.

MYTH: Patients do not know how to assess their own pain.

REALITY: Patients are the best ones to assess their own pain.

MYTH: Children and the elderly feel pain less.

REALITY: It has been shown that children, including premature infants, feel pain. The same is true of the elderly.

MYTH: Many patients somatize.

REALITY: Somatization is rarely seen in patients.

MYTH: There is one way to relieve pain that works for all patients.

REALITY: Each person is different; no single treatment is right for all.

MYTH: Opiates are drugs of last resort.

REALITY: Opiates are used to treat patients with chronic pain and are included in most second and third line treatments.

MYTH: No one understands what I live with.

REALITY: Association québécoise de la douleur chronique is there for you!



My Life with Chronic Pain

For as long as I can recall, pain has been part of my life. I was born in the late fifties with multiple congenital anomalies of unknown origin. By age 13 I had already suffered through some fifteen surgeries. Today I don't even remember where some of my scars came from—I must have gotten them when I was a baby.

Although I was quick to develop tricks for numbing pain, like sliding my leg under my dog's belly or soaking it in a hot water bath, I grew up trying to ignore the pain because I didn't want to think of myself as a handicapped person.

It was my good fortune to have guardian angels, Ms. Gisèle and her son Alain, who often looked after me. They were really very helpful during my toughest times.

As soon I was equipped to walk, around age 4, I started to dance and threw my heart and soul into the practice of numerous sports such as skating, archery, ping pong, swimming, and basketball—all this despite musculoskeletal problems brought about by the overuse of my prostheses. At that time when the sky was the limit, the rehabilitation field had an air of mis-

sionary zeal about it. My prosthetic technicians went along with several of my zany ideas like when I wore higher prostheses to make me taller when I worked in fashion.

Neither my handicap nor my pain could keep me from fulfilling my dreams to drive a car, become a fashion designer, open my own boutique, and sail or travel in Europe and Africa. During the day I was too busy to feel the pain and at night I covered like a wounded animal. I burned the candle at both ends for several decades. And like Édith Piaf said, "No, I have no regrets."

This continued until the day I was no longer able to get out of bed in the morning. My prostheses were confiscated and I was confined to an electric wheelchair. For me it was like being condemned to life sentence. The new wheelchair completely altered my life. Overnight I became a disabled person—something I had never really felt like before. I saw right off that I was starting to write my own obituary.

All those years of taking pain killer medication had finally caught up with me. On January 3, I was hospitalized for 36 hours because of digestive system inflammation. For two months I ate only half a slice of bread and even that was hard to keep down—I was so fragile.

During that time of agony I came to know of Association québécoise de la douleur chronique, which I now think of as my other guardian angel. It gave me hope at a time when I saw no way out. A million thanks to an important AQDC member, Ms. Line B. who welcomed me with unconditional attentiveness.

The Association plays a role as important as that of doctors. It has a place within the multidisciplinary team that treats chronic pain because it focuses on the emotional side of the disease—a part often neglected. I am not criticizing the healthcare system, but the time given to patients is often insufficient. I am, however, lucky to have a good doctor attentive to my needs.

Today AQDC is a key partner in my life. It is a group of peers with whom I share my everyday life. It allows me to stay informed about new treatments and teaches me how to manage my pain and remain active.

I have advice for people suffering from chronic pain: plan your day according to your energy level surround yourself with people you like, include physical activity in your life, and get involved in stimulating projects. Finally, love yourself as you are and join AQDC for free through their website.

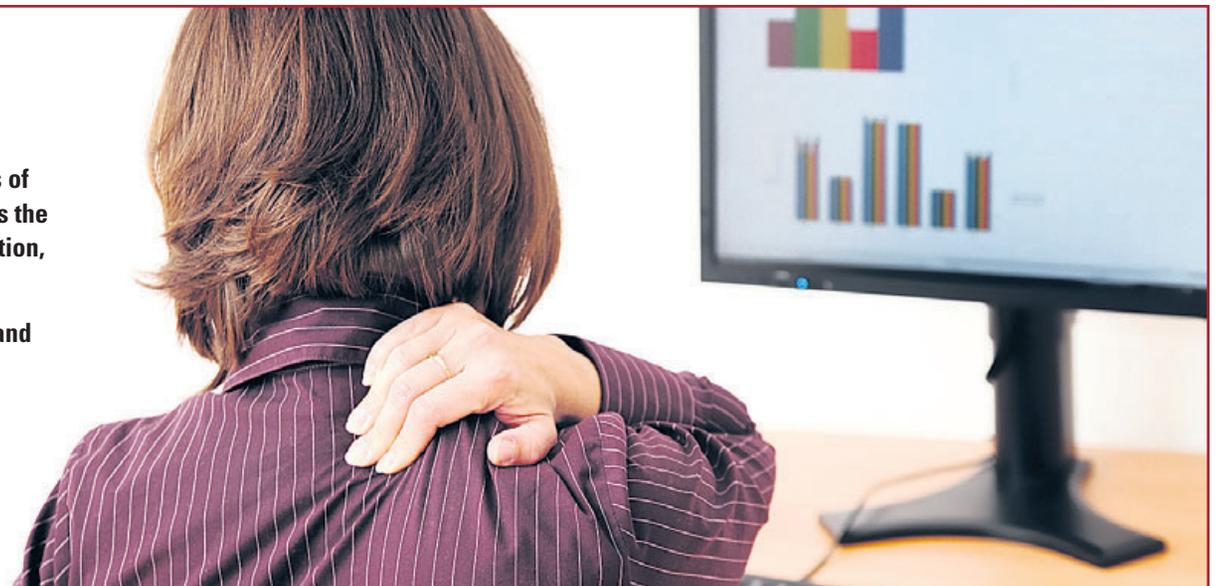
L. M. Lavie



Did you know that...

Refractory pain represents one of the most significant causes of disability reducing quality of life today. In fact, chronic pain is the devastating silent epidemic, affecting over 20% of the population, a prevalence that increases dramatically to 50% with age.

Persons with chronic pain have suffered 7 years on average and nearly half (47%) consider that their pain is not controlled according to the Quebec Pain Research Network (QPRN).



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ASSOCIATION QUÉBÉCOISE
DE LA DOULEUR CHRONIQUE

Pain clinics

QUEBEC CITY REGION

CENTRE HOSPITALIER UNIVERSITAIRE DE QUÉBEC-CHUL

2705 Laurier Blvd, Sainte-Foy

HÔTEL-DIEU DE LÉVIS

143 Wolfe St, Lévis

INSTITUT DE RÉADAPTATION EN DÉFICIENCE PHYSIQUE

525 Wilfrid-Hamel Blvd, Quebec City

MONTREAL REGION

CENTRE HOSPITALIER DE VERDUN

4000 Lasalle Blvd

CENTRE HOSPITALIER UNIVERSITAIRE DE MONTRÉAL - CHUM

Hôtel-Dieu de Montréal 3840, Saint-Urbain St

CENTRE DE RÉADAPTATION LUCIE-BRUNEAU CLINIQUE D'ADAPTATION À LA DOULEUR CHRONIQUE

2275 East Laurier Ave

CHRONIC PAIN MANAGEMENT CLINIC

Montreal Geriatric Institute
4565 Queen-Mary Road

CONSTANCE-LETHBRIDGE REHABILITATION CENTER

7005 West Maisonneuve Blvd

JEWISH GENERAL HOSPITAL- SIR MORTIMER B. DAVIS

3755 Côte-Sainte-Catherine Rd

HÔPITAL DU SACRÉ-CŒUR

5400 Gouin Blvd

HÔPITAL MAISONNEUVE-ROSEMONT

5415 Assomption Blvd

HÔPITAL SAINTE-JUSTINE

3175 Côte-Sainte-Catherine Rd

MCGILL UNIVERSITY HEALTH CENTRE

Hôpital général de Montréal,
1650 Cedar St

MONTREAL CHILDREN'S HOSPITAL

2300 Tupper St

MONTREAL SOUTH SHORE REGION

CENTRE MONTÉRÉGIE DE RÉADAPTATION

1800 Dessaulles St, Saint-Hyacinthe

HÔPITAL CHARLES-LEMOYNE

3120 Taschereau Blvd, Greenfield Park

HÔPITAL PIERRE BOUCHER - GESTION DE LA DOULEUR

1333 Est Jacques-Cartier Blvd, Longueuil

MONTREAL NORTH SHORE REGION

CITÉ DE LA SANTÉ DE LAVAL

1755 René-Laennec Blvd, Laval

HÔPITAL HÔTEL-DIEU DE SAINT-JÉRÔME

290 De Montigny St, Saint-Jérôme

SHERBROOKE REGION

CENTRE HOSPITALIER UNIVERSITAIRE DE SHERBROOKE

3001 North 12th Ave

OTHER REGIONS

CENTRE HOSPITALIER DE GASPÉ (PAVILLON HÔTEL-DIEU)

215 York West Blvd, Gaspé

CENTRE HOSPITALIER RÉGIONAL DE RIMOUSKI

150 Rouleau Ave, Rimouski

CENTRE HOSPITALIER ROUYN-NORANDA

4 9th St, Rouyn-Noranda

CHRTR - PAVILLON SAINTE-MARIE

1991 Carmel Blvd, Trois-Rivières

CLINIQUE ANTIDOULEUR CSSSÎ

45 Père-Divet St, Sept-îles

CSSS DOMAINE-DU-ROY

45 Brassard Ave, Roberval

CSSS MARIA-CHAPDELAINÉ

2000 Sacré-Cœur Blvd
Dolbeau-Mistassini



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AQDC-11-2006-A

Amount of the donation:

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You can register on line on our Web site : www.chronicpainquebec.org

Or send this form to: **Association québécoise de la douleur chronique**
61, Maison de la poste, Montréal (QC) H3B 3J5

The Association québécoise de la douleur chronique (AQDC) is a charitable organization (N/E 860295633RR0001) which representing people suffering from chronic pain in Quebec.