

ACTION Ontario

2010 Annual Report



A Year in Review

2010 marked a year of exceptional accomplishment for ACTION Ontario, a small not-for-profit organization comprised of healthcare professionals, researchers and patients, with a shared goal of improving awareness, diagnosis and treatment for neuropathic pain sufferers.

The Growth of ACTION PNP

The year 2010 quickly shaped up to be the “unofficial” year of patient input in the province of Ontario and ACTION Ontario/PNP proved to be a leader amongst patient advocacy groups. Due to the tremendous efforts and strength of the ACTION PNP Steering Committee, ACTION PNP membership rose to over 250 in 2010. The “patient voice” of ACTION PNP could be seen everywhere. OUCH, ACTION Ontario’s advocacy newsletter, made its way from government offices to doctors’ offices to patients’ homes. ACTION PNP members were heard at the Canadian Pain Society Conference in Calgary, where ACTION had a booth, as well as in the legislature at Queen’s Park. ACTION PNP also provided input to the Canadian Agency for Drugs and Technologies in Health on the patient input process for the Common Drug Review.



ACTION PNP Chairperson David Harlow and Co-chair Janice Frampton at the Canadian Pain Society Conference, April 2010

Action around Bill 101

In August of 2010, the Ontario government introduced a narcotics strategy aimed at tackling the inappropriate use of prescription narcotics such as oxycodone. In support of this strategy, the government introduced legislation in September 2010 in the form of Bill 101: An Act to provide for monitoring and dispensing of certain controlled substances. People living with chronic pain often use opioids to help manage their pain, so when the government decided to move forward with this legislation, ACTION knew it had to use this opportunity to stress the need for a pain strategy for Ontario.

Few concerns were raised publicly about Bill 101 at the time of its introduction. However, one of the key goals of ACTION was to ensure that chronic pain patients who were in need of prescription narcotics to manage their pain did not have their access limited.

ACTION’s advocacy success was evident. Few spoke of a strategy to deal with chronic pain before last fall, but now it is a top issue at Queen’s Park. Throughout the course of the debate on Bill 101, which was passed into law at the end of November 2010, discussion of the need for chronic pain strategy was raised in the legislature by all political parties, including a

commitment by the government to address the current shortcoming in chronic pain treatment and management.

“The Narcotics Advisory Panel to the Ministry of Health has a long-term mandate to provide advice to government on optimal pain management; and the Ministry of Health and Long-Term Care is working to establish a group of experts in the field of chronic pain, including physicians and other providers, to develop evidence-based recommendations for chronic pain management. This advice will inform a strategy to organize and deliver more effective treatment and management programs for those people who have chronic pain issues,” Liz Sandals, Parliamentary Assistant to the Minister of Health and Long-Term Care, during Bill 101 debate.

ACTION Ontario’s Queen’s Park Day

ACTION Ontario hosted its first Queen’s Park Day at the Ontario Legislature on November 1, 2010 — advocating not just for neuropathic pain patients but also on behalf of all chronic pain sufferers in Ontario, with the ultimate goal of establishing a comprehensive pain strategy for the province. It required careful planning and was timed to coincide with the debate on Bill101.

Throughout the day, delegations comprised of ACTION Ontario Board members, PNP members and an H&K representative conducted meetings with targeted MPPs and their staff. A total of 10 meetings (eight MPP and two with political staffers) took place throughout the day. At lunchtime, a reception was held in the main legislative building that was well-attended by MPPs, cabinet ministers and representatives from partner organizations such as the MS Society and the Canadian Paraplegic Association. ACTION Ontario’s Chairperson, Dr. Angela Mailis-Gagnon, talked about neuropathic pain in her usual passionate way, providing expert advice and possible solutions to the problems faced by pain patients. A very moving speech from ACTION PNP’s Chair Janice Frampton delivered a very personal and moving speech. ACTION was also proud to have the Hon. Deb Matthew, Minister of Health and Long-Term Care, speak, along with both opposition health critics: Christine Elliott (PC), MPP for Whitby-Oshawa and France Gélinas (NDP), MPP for Nickel Belt.

After the reception, Dr. Helena Jaczek, MPP for Oak Ridges-Markham, welcomed ACTION to the legislature and read a member’s statement in support of ACTION Queen’s Park day.

Overall, ACTION Ontario first Queen’s Park Day was considered an overwhelming success with pledges of support from MPPs from all parties to assist in raising awareness about chronic pain and to move towards the establishment of a comprehensive pain strategy for the province of Ontario.

Dr. Helena Jaczek: Chronic pain affects nearly 20% of Ontarians, and 60% of those are over the age of 65. Today, I had the opportunity to meet with members of Action Ontario, as have many of my colleagues. I would like to welcome Action Ontario, which is here for their inaugural Queen's Park day to increase awareness about chronic pain.

Action is an innovative, non-profit organization made up of doctors, researchers, health care professionals and patients committed to seeing improvements in the diagnosis and treatment of Ontarians who suffer from neuropathic pain and other forms of chronic pain.

Neuropathic pain destroys careers, relationships and even the will to live. Its direct impact on health care costs is estimated to now exceed \$250 million annually, with a broader impact on lost income and productivity estimated at several billion dollars per year.

On November 9, during National Pain Awareness Week, Action will be holding their national symposium at the MaRS Centre with a theme of patient input for system change, and I encourage all members to attend.

I would like to especially thank Dr. Angela Mailis-Gagnon, a constituent of mine and the chairperson of Action Ontario, for her hard work and dedication to this organization. On behalf of the government, I want to extend a sincere thank you to all volunteers at Action Ontario for the work they are doing on behalf of Ontarians suffering from pain.

Patient Input for System Change **2010 National Pain Awareness Week Symposium**

ACTION Ontario's 2010 *National Pain Awareness Week* symposium had as its objective to share ideas on how our health system can more effectively meet the needs of Ontario's chronic pain patients.

More than 100 people attended the symposium, which was held on November 9, 2010 in the MaRS centre auditorium. Importantly, it was a diverse group, with representation from patients (43%), family members/caregivers (14%), physicians (12%), other healthcare providers (10%), as well as other stakeholders (18%) such as researchers, government, industry and non-governmental organizations.

Dr. Angela Mailis-Gagnon, ACTION's chairperson, open the symposium with a presentation on the challenges facing chronic pain patients in Ontario's health system, current approaches to treatment, and recommendations to improve the system with a coordinated, stepped approach that follows a chronic disease model. Dr. Mailis-Gagnon also discussed the cost of the current uncoordinated approach, both to the patient and in terms of effective use of health system resources.

From the mouths of those living chronic pain

Like previous ACTION symposia, a highlight once again was the patient panel. The panel discussed how the wait times to see specialists are anywhere from six to eight months while they are left to struggle with their pain. The overwhelming frustration from the patient panel was the lack of diagnosis at the primary care level. One panelist, Will Geerts, saw 40 doctors before he finally found relief at the clinic of Dr. Angela-Mailis Gagnon. They questioned how a system which allows for this kind of inadequacy can be cost effective for the government, the taxpayer and the end user, the patient.



The youngest panelist, 17-year-old Veronica Dunlop, who suffers with Complex Regional Pain Syndrome, would like to see a clinic in Ontario such as the one in Philadelphia where she is headed. While recognizing the expense of these clinics she says, “Surely seven years worth of appointments with specialists plus many x-rays, ultrasounds, MRIs and bone scans costs even more.”

The panelists discussed the need for more and varied treatments for chronic pain sufferers such as acupuncture, tens and physiotherapy. As well as the need for more diverse medication for the treatment of neuropathic pain.

Ann Tuzi, talked to the need for more financial support for the chronically disabled in the form of disability cards, much like seniors cards, offering discounts to the disabled. She also suggested the need for financial support from government in the form of property tax breaks resembling those offered to seniors.

Phil Frampton rounded off the panel with the important perspective of the caregiver, highlighting the impact chronic pain has on those around and supporting the patient.

Action Ontario’s symposium *Patient Input for System Change* provided pain patients, caregivers, and clinicians with a voice that is so seldom heard in tandem. This symposium was in essence a bridge for clinicians, patients and their caregivers to meet in a public forum, thus expressing their requirements for improved pain management and their challenges dealing with our current health system in Ontario. The urgent need for a Comprehensive Pain Strategy has never been so apparent. I am now hopeful that change is imminent.
– Julie Feldman, PNP Steering Committee Member

Patient self-management

Dr. Durhane Wong-Rieger, president and CEO of the Institute for Optimizing Health Outcomes, empowered patients with a discussion on self-management — techniques for the patient to better manage and control their chronic health condition.

The Alberta experience

Dr. Paul Taenzer, one of the newest members of the ACTION board and one of the founders of Canada's first coordinated pain systems, described the path they took to achieve the comprehensive pain system in the Calgary Health Region, and shared lessons for Ontario.

Audience input

The symposium concluded with a question-and-answer period, as well as an opportunity for audience members to provide input on the need for system change. We heard that to better meet the needs of patients, participants thought the improved pain education for healthcare providers and development of a coordinated system needed to be addressed first. We also learned that 53% of those at the symposium believe that the difficulty in getting a correct diagnosis most affects people with chronic pain, and that 37% felt that access issues – to medications, devices or other therapies – most affected patients.

ACTION Ontario would like to thank its sponsors

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Appendices



SUBMISSION TO THE STANDING COMMITTEE ON FINANCE AND ECONOMIC AFFAIRS

February 3, 2010

The Need to Tackle Chronic Pain in Ontario

ACTION Ontario appreciates the opportunity to provide input on the 2010 provincial budget to the Standing Committee on Finance and Economic Affairs. While we appreciate the Government of Ontario is operating in a very trying fiscal environment, it is in the government's best interest to put in place a strategy that can address the shortcomings in how we currently deal with chronic pain, so that this escalating health problem is better managed, as are health system resources employed to tackle the problem.

About ACTION Ontario

ACTION Ontario, a non-profit organization comprised of doctors, researchers, other health-care professionals and patients, advocates on behalf of neuropathic pain sufferers. ACTION Ontario is committed to increasing awareness about the cost of neuropathic pain and to seeing improvements in the diagnosis and care of people with neuropathic pain.

What is neuropathic pain?

Neuropathic pain is a particularly debilitating form of chronic pain that can rob people of their quality of life and the ability to sleep, work and undertake daily activities. Neuropathic pain results from injury or disease of the nerves, the spinal cord or the brain and has many causes, including multiple sclerosis, diabetes, AIDS, cancer and spinal cord trauma. More than one million Ontarians suffer with neuropathic pain. When you include other forms of chronic pain, the number of sufferers ranges from 20 to 30 per cent of the population, or 2.4 to 3.6 million Ontarians.

The problem

In Ontario, the current system for chronic pain care is uncoordinated and imbalanced, leaving many patients misdiagnosed, inappropriately or under treated, and suffering. Treatment of complex chronic pain like neuropathic pain can be highly specialized and requires a comprehensive approach to be optimally effective. Of critical concern is the fact that access to the best, evidence-based, treatment that are appropriate to each individual (medications, spinal

cord stimulators, implantable pumps, psychological therapies, exercise therapy, etc.) are often unavailable or must be paid for out of pocket by the patient.

For those suffering from neuropathic and other chronic pain, the problem is magnified by the fact that there is very little awareness amongst policy makers, the insurance industry, medical professionals and the public about chronic pain.

Currently, there is very little chronic pain education in Canadian medical schools and there is no formal training or certification for pain experts in Canada. Indeed, a 2007 survey of training programs at 10 major universities across Canada found that graduates in medicine, dentistry, nursing, pharmacy and other healthcare professionals lagged far behind veterinary medicine graduates in the amount of designated training time they received on pain diagnosis and management in general. The survey, which was commissioned by the Canadian Pain Society, actually suggests that veterinary medicine students receive over three times more pain-specific training than most healthcare professionals.

Where there are multidisciplinary pain clinics, and there are few in Ontario, patients often face long waiting lists to access the clinicians who do understand their pain. Those who are not able to get a proper diagnosis or effective pain management often self-medicate with alcohol and drugs. Addictions to these substances then lead to a whole host of other societal problems.

We cannot afford to ignore the problem of chronic pain

Chronic pain is a serious public health concern, as it affects 20-30% of Ontarians, and is one that is only expected to grow as our population ages. And it is a costly problem. The National Population Health Survey 1996-1997 estimated that chronic pain costs the Canadian economy approximately \$14,744 per affected person per year — which translates to \$35 to \$53 billion annually in Ontario alone.

A Danish study published in 2003 found that patients with chronic pain experience twice as many days missed at work, are seven times more likely to quit their job due to health concerns, make twice as many contacts with healthcare professionals and use 25% more healthcare resources (Dr. Roman Jovey, Canadian Pain Society, 2005).

It's Time to take ACTION on chronic pain

The frustrations of both patients and their physicians, along with researchers and other individuals concerned with neuropathic pain, was the catalyst behind the creation of ACTION Ontario, with the goal of furthering awareness, education and access to treatment. Those involved with ACTION Ontario strongly believe that the province urgently needs an overall provincial pain strategy that addresses the treatment of chronic pain through a comprehensive approach. This integrated strategy would give clinicians the tools to better manage the disease with improved results, while making more effective use of health care resources.

Other Canadian jurisdictions, such as Nova Scotia, Quebec and Alberta, have successfully implemented comprehensive pain strategies. These strategies are generally based on a chronic disease management model that involves a continuum of care, interdisciplinary teams, education and systems to enable patient self-management, continuing education for health professionals, and health promotion and prevention. Lessons from these strategies can be applied to Ontario to enable the development of a comprehensive pain strategy without recreating the wheel.

In order to properly address the unmet need and remove the barriers that stand between patients and the help they need, Ontario needs a comprehensive strategy for chronic pain developed in consultation with experts in the area, including ACTION Ontario.

Respectfully submitted,

ACTION Ontario



Comprehensive pain strategy needed to address misuse of narcotics in Ontario

TORONTO (August 27, 2010) — ACTION Ontario, a non-profit group advocating on behalf of chronic pain sufferers, welcomes the announcement of a provincial narcotics strategy and encourages the government to act on the underlying issue of chronic pain.

“The government’s strategy is a good first step in tackling the narcotics issue, but we also need to address the underlying problem of how we treat chronic pain in this province,” said Dr. Angela Mailis-Gagnon, the chair of ACTION Ontario and founder and director of the Comprehensive Pain Program at the Toronto Western Hospital. Dr. Mailis-Gagnon is also a member of the provincial narcotic advisory panel, as well as the National Opioid Use Guideline Group. “We need a comprehensive strategy that addresses how pain is diagnosed and managed, including access to a variety treatment options.”

Janice Frampton, a 53-year-old Pickering resident and co-chair of ACTION’s patient advocacy arm, has struggled with debilitating pain her entire life from a congenital condition called Tethered Spinal Cord Syndrome. “I know from my own experience people will take whatever they need to, and in increasing quantities, to try and escape their pain. I drank heavily in an attempt to manage my pain,” said Frampton. “Finally, after being properly diagnosed and treated, I am able to manage my pain and my life appropriately.”

“We need to look at the bigger picture. Medications and treatments are only as good as the physicians who prescribe them and the knowledge of the patients who receive them. This cycle of overprescribing narcotics for chronic pain will continue until patients choose to educate themselves as I did. There is no cookie cutter approach to treating pain. A comprehensive pain strategy is key to addressing this complex problem.”

Other Canadian provinces, like Alberta, Quebec and Nova Scotia, have successfully implemented pain strategies that could help inform the Ontario experience. Chronic pain is an escalating health problem affecting 20-30% of Canadians and it has been estimated that chronic pain costs the Canadian economy approximately \$6 billion a year.

ACTION Ontario, a non-profit organization comprised of doctors, researchers, other health-care professionals and patients, advocates on behalf of neuropathic pain sufferers. Neuropathic pain is a particularly debilitating form of chronic pain. ACTION Ontario is committed to increasing awareness about the cost of neuropathic pain and to seeing improvements in the diagnosis and care of people with neuropathic pain. For more information, please visit www.actionontario.ca.

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Narcotics legislation first step, must now address pain

TORONTO (September 15, 2010) — ACTION Ontario, a non-profit group advocating on behalf of chronic pain sufferers, applauds the provincial government’s Narcotics Safety and Awareness bill and encourages the government to take the next step and also address the underlying issue of pain with a comprehensive strategy.

“As a member of the province’s narcotics advisory panel, I know how important it is that we address the growing narcotics problem in this province,” said Dr. Angela Mailis-Gagnon, chair of ACTION Ontario and founder and director of the Comprehensive Pain Program at the Toronto Western Hospital.

“However, we must not overlook that the root of the opioid public health crisis lies in the poor diagnosis and management of chronic pain. We need to embark on a comprehensive pain strategy in order to fully address the opioid crisis and to better meet the needs of the millions of Ontarians who suffer from chronic pain.”

Currently, patients with chronic pain face a disjointed system of care and varying levels of knowledge from healthcare practitioners on how to diagnose and effectively treat pain.

“My clinic is overwhelmed by patients who come to me on high doses of narcotics and should not be. They’ve been prescribed these drugs because their physicians have not had the appropriate pain training, or because certain non-opioid medications or non-pharmacological therapies are not covered by the current system. On the other hand, we cannot ignore the other side of the problem, as thousands of Ontarians, particularly the elderly, who could benefit from appropriate doses of opioids, have no access to these drugs as physicians refuse to prescribe them. The problem here is loss of balance,” said Dr. Mailis-Gagnon.

“Each pain patient and situation is unique in its own right, yet somehow we are all lumped together,” said Janice Frampton, who has struggled with debilitating pain her entire life and is co-chair of ACTION’s patient advocacy arm. “Something must be done to rectify this situation in the form of education and a comprehensive pain strategy or there will be more addiction, more social upheaval and more strain on our healthcare system.”

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Presentations to the Standing Committee on Social Policy – Bill 101

ACTION PNP

The Chair (Mr. Shafiq Qadri): I now invite our next presenter to please come forward, Ms. Frampton, the co-chair of Action PNP, people with neuropathic pain. Welcome, Ms. Frampton. You have 10 minutes in which to make your presentation. I'd invite you to please begin now.

Ms. Janice Frampton: Good afternoon. My name is Janice Frampton. I am the co-chair of Action PNP, or people with neuropathic pain, the patient advocacy arm of Action Ontario.

Action Ontario is a non-profit organization made up of physicians, other health care workers, researchers and patients who are advocating on behalf of neuropathic pain and other chronic pain sufferers.

I would like to thank you for this opportunity to speak before the Standing Committee on Social Policy on Bill 101.

Seven years ago I was diagnosed with a rare neurological birth defect called tethered spinal cord syndrome. This syndrome occurs when the spinal roots at the end of the nervous tissue are tangled up in scar tissue. It is degenerative and closely linked to spina bifida.

For the first 46 years of my life I lived with misdiagnosed, untreated neuropathic pain. Neuropathic pain is a particularly debilitating form of chronic pain that is the result of injury or disease of the nerves, spinal cord or brain. And because my pain went misdiagnosed and untreated, I self-medicated with alcohol to cope. The worse the pain became, the more I drank, until I could drink no more, because death was quite literally tapping me on my shoulder.

Eventually, I ended up in a rehab centre, not here but in the United States. When I arrived at the Betty Ford Center with my bagful of pills, it was discovered that I was indeed an addict, but not to opioids; I was addicted to antidepressants. Why? Because the doctors I was seeing at the time were convinced that I wasn't in pain, I was just depressed and the pain I was experiencing was all in my head. So they loaded me up with antidepressants even though they knew I was drinking—a very lethal combination. Misdiagnosis, untreated pain, addiction—a vicious cycle that didn't include opioids.

So what does my story have to do with the debate around the narcotics legislation in the province of Ontario? Quite literally, everything. A correct diagnosis and treatment by physicians properly trained in the field of pain and pain management would have alleviated years of suffering not only for me but my family, not to mention the thousands of dollars it would have saved the provincial health care system. Sadly, my story is not unique, which illustrates one of the tragedies of our system and the potential harm of this legislation if it is left to stand as is.

Too many actual pain patients are misdiagnosed and denied proper medication and treatment. These patients may end up going down destructive paths to alleviate their pain while the wrong medications are over-prescribed for other people, possibly causing the same addictive cycle without relief.

Opioids themselves aren't the enemy and putting the fear of God into physicians who prescribe them isn't the answer and could cause more damage. Let me give you an example. After the introduction of Bill 101 on September 15, one woman blogged three times within a matter of 12 hours in a panic because her family doctor now refused to refill her opioid prescription, using the legislation as his excuse.

So what is the solution? First and foremost, it is education: Education of physicians about chronic pain in general, including more time spent in the classroom itself, especially primary care physicians who deal with about 90% of pain patients. As the last woman said, veterinarians receive more education in pain treatment than our physicians do.

Patient education and awareness programs must also be part of this process. For the record, narcotics are included in my pain management program, but because of my own experiences, I have become very self-aware. I know what works for me and what doesn't and I do not take medications just because they are prescribed for me.

Channels of communication between all health care providers, including but not limited to physicians, pharmacists and nurses, must be established. It is vital that these gateways be opened. Family doctors need to be properly equipped in order to diagnose and treat chronic pain in its early stages. This can be done by giving them access to psychologists, nurses, self-management support systems and prevention tools like vaccines.

Chronic pain patients all tend to be lumped together. To be blunt, you wouldn't lump all cancer patients together; you would determine what kind of cancer a person has. So why is someone with neuropathic pain treated the same as someone with arthritis or sciatica? Because pain is considered subjective and is not necessarily visible to the human eye—it is often considered to be all in a person's head. But if someone who has cancer is in pain, they would be treated accordingly. Think about it. The truth of the matter is: We are not all the same; our pain is not all the same. And this, in part, is why so many narcotics are over-prescribed. Because isn't that what you give someone who is in pain? Narcotics? Around and around it goes.

To this end, there need to be more options in the management of chronic pain. This means improved access for pain medications other than just narcotics and more options such as psychological treatments, physical therapy and other complementary treatments.

The province needs to establish standards and outcome measures for pain clinics. This will also help to reduce waste within the current system, such as with block shops or nerve block and soft tissue injection clinics. According to a Toronto Star article, when OHIP audits were stopped in 2003, the cost of these injections was \$24.4 million. In 2005, this number jumped by 44% to \$33.1 million. Based on these numbers, this amount will have more than doubled to \$67 million a year in 2010 dollars. These clinics also dispense a large cocktail of medications, including narcotics, to the clientele, who usually visit them once or twice a week. They're called pill mills.

Having said all this, what Ontario needs are properly trained, licensed pain physicians. Right now, there is no such thing as a pain specialty in Canada.

Before I conclude, I'd like to take a moment to talk about insurance companies. Please consider this: Once this legislation is in place and a pain patient has gone over their quota, you can rest assured that an insurance company will cut that patient off. It won't matter if they have cancer or have undergone five spinal surgeries to correct a tethered spinal cord; the insurance companies will use this legislation to impose limitations and restrictions on their clientele that will cause more emotional, financial and physical strain on the patient—in other words, more pain. This potentially means no more medications, more substance abuse, and the cycle will continue. Remember, you don't need a prescription to go to the LCBO. There will always be someone there to sell something to someone, and a pain patient will do anything to alleviate their pain. Believe me, I know.

This may sound desperate, but desperate people do desperate things. Remember the lady blogging? There will always be people who circumvent the system. You know that, and I know that. What would you do?

This legislation may be a good first step in tackling the issue of narcotics overuse in the province of Ontario. But unless we address the underlying issue of pain itself and the treatment of pain patients with the introduction of a comprehensive pain strategy for the province of Ontario, we will continue on the same myopic path and the same cycle of destructive, addictive behaviour.

Once again, on behalf of Action PNP, Action Ontario and pain sufferers without a voice in the province, I ask you all to consider a comprehensive pain strategy in Ontario. Without this step, we won't be able to truly tackle the narcotics problem. Thank you.

The Chair (Mr. Shafiq Qadri): Thank you, Ms. Frampton. I believe we will go to the PC Party: Ms. Jones. About 30 seconds per side.

Ms. Sylvia Jones: Thank you for your presentation. You mentioned pain specialties. Are you familiar with other jurisdictions that would have that option?

Ms. Janice Frampton: Alberta.

Ms. Sylvia Jones: Alberta does?

Ms. Janice Frampton: Alberta, and I believe one of the provinces on the east coast; I think it's Nova Scotia.

Ms. Sylvia Jones: Thank you.

The Chair (Mr. Shafiq Qadri): Madame Gélinas.

Mme France Gélinas: Are there centres of excellence in Ontario where they know how to look after pain?

Ms. Janice Frampton: Well, the one I go to: Dr. Mailis. She'll be presenting later. She saved my life.

Mme France Gélinas: Thank you.

The Chair (Mr. Shafiq Qadri): Ms. Sandals.

Mrs. Liz Sandals: I believe she is appearing later, so she may be the better person to ask, but are there protocols that will help us determine the legitimate use of pain medications versus overuse and abuse?

Ms. Janice Frampton: There are. That's why I say there has to be more education at the primary care level, because there is a lack of diagnosis there, and that's where everybody comes filtered to—

The Chair (Mr. Shafiq Qadri): Thank you, Ms. Frampton, for your deputation

DR. ANGELA MAILIS-GAGNON

The Chair (Mr. Shafiq Qaadri): I'd now invite our next presenter to please come forward, Ms. Angela Mailis-Gagnon. Welcome, Ms. Mailis-Gagnon. You've seen the drill. You've 10 minutes in which to make your presentation—

Dr. Angela Mailis-Gagnon: I'm very aware.

The Chair (Mr. Shafiq Qaadri): Yes, please begin.

Dr. Angela Mailis-Gagnon: I'm Dr. Mailis-Gagnon. I'm the head of the comprehensive program of the Toronto Western Hospital University Health Network, I'm a senior investigator with the Krembil Neuroscience Centre at the University Health Network, I'm a full professor of medicine at the University of Toronto and I hold a master's of science degree as well, except in my specialty in physical medicine. I'm a popular science writer and my book *Beyond Pain* was published in Canada in 2003 and 2006, and in the United States as well. I'm a science writer for the Canadian Association of Retired Persons' electronic newsletter, the Advocacy newsletter, and my column is read by 80,000 people every two weeks across the country, 60% of whom are coming from Ontario.

I'm also the chair of the patient advocacy group for education and advocacy on neuropathic pain and chair of Action Ontario, and additionally, I had the honour of being a member of the Narcotics Advisory Panel of Helen Stevenson, now Diane McArthur, and Deb Matthews. So I have total knowledge of the problem.

I practised pain management for 28 years, and my unit has been the only one funded in the whole of the province by the Ministry of Health for the last 20 years. That's the only reason why I have survived with my team, simply because we have gone on salary, as the current system for fee-for-service does not really serve patients with pain.

Having given you my credentials, I have seen in 28 years over 20,000 patients with chronic pain. I'm one of the founders for the University of Toronto's Centre for the Study of Pain. So I come with a lot of baggage and a lot of patients with me.

Having said all of that, of course I will support Bill 101; I was part of the group that created it. But this is only treating the symptom of a disease. If you think that Bill 101 is treating the disease, it's a mistake, because opioid abuse is only an outcome of a broken-down system that never existed in the first place. You cannot treat chronic pain if you're not educating your physicians and your health care providers from within the school. You cannot get out trained physicians if they receive five times less training in medical schools than a veterinary doctor who's going to treat your dog—your dog would have better treatment than my patients would. And when they come out there with no training and with a population of which one third has experienced or will experience pain, the physicians have no resources at the primary care level—(1) 90% of all pain is treated by the primary-care-level physicians, who have no training; (2) there are no resources for those physicians; (3) there is no time, because the current system of fee-for-service does not remunerate for time. It takes 30 seconds to write a prescription for opioids and 30 minutes to scratch the surface of a chronic pain patient.

Then you go a lot higher. You say, "We need pain clinics." But there is no formal training in this country. None of us has any training in this country. There is a process now to try to establish a subspecialty at the Royal College level. It's going to take many years. People try to get the training through continuous medical education, but there are now absolutely no standards in this whole country about who is a good pain clinician and who is not.

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Many of us work there for the love of our hearts because this is what we love doing, against all odds, working very long hours. Others will use the system because there are only very few things in the system that are remunerated. One of those is nerve blocks. One of my patients already spoke to you about the cost of nerve blocks: \$24.3 million in 2003. When the audits were stopped in OHIP, it went to \$33.1 million. By estimates, today the cost to the system will be \$67 million.

I'll give you an example. I saw a patient the other time, and this is a real patient, and he said to me, "Excuse me; follow up? Let me see if I can fit you in my book. Monday, Wednesday and Friday I have my blocks." He had these blocks for three years, three days a week, and he said, "Oh, by the way, I have a few emergency visits in a month," because the clinic is operating seven days a week at a cost to OHIP. On the other hand, we talk about the abuse of opioids, and you heard all my other co-speakers, and they know very well there's no question about that. This is a big issue. I just saw a patient—this is really true—and he had Crohn's disease. He was on 180 tablets of Dilaudid—eight milligrams a day—plus 200 micrograms of a Duragesic patch. Let me give you the numbers in morphine equivalent. He was on 9,360 milligrams of morphine equivalent a day for the number of 5,400 Dilaudid tablets that he was taking. I asked the pharmacist about the cost, and the cost to the pharmacy was \$3,350.39 a month for an amount of \$40,740.75 a year, all paid for by the Ontario drug benefit program. This is one of the things that Bill 101 tries to establish and correct, but it would be a major mistake—if this committee goes out of here and says the narcotics, the doctors will be chilled off. They won't prescribe. I tell you, they don't prescribe now. What we are facing is the dual tragedy of pain: We have a bunch of doctors or physicians or patients who abuse or overuse the medications, and we have hundreds of thousands of others who are under-treated. Opioids may make the difference between them being in bed and walking out. I have 92-year-old patients that I treat with morphine drops and I get all the hugs and the kisses because grandpa, instead of being in bed for eight years, is out there travelling to Holland. This is a reality: The dual tragedy of the bad management of pain is happening right now. That is what we cannot afford to miss.

Having said all of that, what do we do for a problem that is huge? First of all, all governments, all provinces shy away from a comprehensive strategy on pain. For what reason? "My God, it will be very expensive." Well, you don't establish new programs to clean up the mess without spending, but I would say to you, because I'm very fiscally responsible and I have operated on a government shoestring for 20 years—mind you, this government and all the other governments have never given an increase in my program for 10 years. But that's irrelevant; nevertheless, I survived. However, when you look at that, you have a waste in the system that you have to correct. First of all, look at the system where you are and cut the fat, rearrange resources, reallocate resources, and then when you look at a comprehensive pain strategy, from the primary care level all the way to the subspecialty clinics, go in steps. Look at the landscape first, all of the elements, all the players, all the stakeholders. Connect the dots. Never put a strategy in place if you don't have fiscal responsibility and if you don't have outcome measures. If you don't have metrics, if you don't have performance indicators to make sure that the thing you put in place works, don't put it in place.

This is indeed a complex issue, but it can be accomplished across a chronic disease model, very carefully bringing on the stakeholders.

The last thing that I want to tell you, because I'm about to finish: Don't think you're inventing the wheel or reinventing the wheel. Alberta: The Calgary region has already had a comprehensive strategy for 16 years. We are lucky to have imported from Calgary one of the godfathers of this strategy, who is now a permanent resident of Ontario. So there are others who have done that. Quebec has almost the form of an octopus in a very comprehensive strategy. Look at other jurisdictions in Canada. Don't reinvent the wheel.

It is possible that things can be done. They need care. They need comprehensive management from the bottom all the way to the top. What you have to ask is not only what it's going to cost us to do it, but what it's going to cost us if we don't do it.

Thank you very much. I finished in time, sir.

The Chair (Mr. Shafiq Qadri): Thank you, Professor Mailis-Gagnon. We only have 20 seconds a side, beginning with the PCs.

Ms. Sylvia Jones: Thank you.

The Chair (Mr. Shafiq Qadri): Madame Gélinas.

Mme France Gélinas: What would you like to see as an outcome measure?

Dr. Angela Mailis-Gagnon: As an outcome measure, I would like to see, for example, the number of patients who are treated at the primary care level who would never need a clinic like mine. I would like to

see—just to get a primary care understanding of what pain they have and what percentage of these people will go into—

The Chair (Mr. Shafiq Qadri): Thank you.

Mrs. Liz Sandals: Actually, I had the same question, so keep going.

Dr. Angela Mailis-Gagnon: Yes. That would be one of the outcome measures you would like to have, and then there should be other kinds of metrics. For example, if you are going to put in place comprehensive pain teams, establish in advance what are the standards and credentials for these kinds of teams. When you establish them, find out what kind of people they treat, how many times they need to treat them, do they keep a revolving door, going there forever, and find out—

The Chair (Mr. Shafiq Qadri): Thank you, Ms. Sandals, and thank you, Professor Mailis-Gagnon, for your deputation. As I did mention earlier, please feel free to submit any further questions or comments in writing to the committee.