

## OUCH

### Optimism and Understanding Creates Hope

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#### Neuropathic Pain—Background

The International Association for the Study of Pain (IASP) describes pain as a unpleasant personal experience that involves both a sensation and an emotion. We experience pain when we have an injury to our body, when we fear that an injury is impending and even in cases where there is no injury at all. In other words, pain is always personal and the person who feels the pain is the one who can best describe it.

There are several kinds of pain. The pain from injury to the muscles, tendons and ligaments or from a broken bone is different that the pain from injured nervous tissues (such as the nerves in our arms and legs, the spinal cord or the brain). This last kind of pain is called Neuropathic Pain.

Neuropathic pain is estimated to affect up to 7-8% of the general population. This means that close to 2.5 million Canadians (1 million in Ontario alone) are affected by this type of pain.

NP can be the result of numerous conditions such as: stroke; trauma to the spinal cord (a devastating injury that leaves the patient para-

lyzed); Multiple Sclerosis (a disease that causes inflammation to the nerves, spinal cord and brain); syringomyelia (a condition caused by cavities (holes) in the spinal cord); damage to the nerve roots after a herniated disc (not treated for long time) or after unsuccessful back surgery; brachial plexus injury (a serious injury that may leave the patient with extremely painful but weak or paralyzed and insensitive arm); pain after amputation (when the patient complains bitterly of pain in the amputated "ghost" arm); diabetic neuropathy; other neuropathies due to AIDS or treatment with cancer medications; complex regional pain syndrome (a difficult condition affecting a limb even after trivial injuries); post-herpetic neuralgia (the painful condition that follows an attack of shingles); trigeminal neuralgia; injuries to the nerves of the arms, legs or body after trauma; surgery that damages nerves (such as pain after mastectomy for cancer, cardiac bypass surgery, surgery to repair abdominal hernias or inguinal hernia), and the list goes on.

In many of the conditions listed above, pain is affecting



a large number of patients. For example, pain affects 6-8% of the patients after stroke, 70% or more of the patients after spinal cord injury, 7-54% of patients with AIDS, up to 65% of patients with Multiple Sclerosis, up to 90% of patients with syringomyelia, 50-75% of patients with amputation, most patients with nerve injury after trauma, almost half of the patients with shingles who are 70 years or older, up to 25% of the women after mastectomy, and 15% of patients after cardiac bypass surgery.

NP is a debilitating and very difficult type of pain to diagnose and treat. It robs sufferers from their sleep, enjoyment of life, work and role within the family and it costs million of dollars to the health care system. To learn more about NP, what causes it and how to treat it, join [www.actionontario.ca](http://www.actionontario.ca).

#### Did You Know?

If you forgot or were unable to submit income taxes due to illness, or have just simply fallen behind on your payments, the Federal government has set up the Fair Tax Commission. Through a letter outlining the circumstances of your situation, you can appeal penalties and interest owed to the government. Fair Tax Commission offices are located in all Revenue Canada locations.

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Dr. Angela Mailis-Gagnon, MD,  
ACTION Chairperson

## Dr. Angela Mailis-Gagnon

Dr. Angela Mailis-Gagnon was born in Athens, Greece where she obtained her medical degree from Athens Medical School in 1976. She received specialty training in the field of Physical Medicine and Rehabilitation in Toronto and became Fellow of the Royal College of Physicians of Canada in 1982. She also obtained a Master degree from the Institute of Medical Science, University of Toronto, Canada in 1988. She specializes in Chronic Pain and founded the Comprehensive Pain Program of

the Toronto Western Hospital in Toronto, Ontario, in 1982, a nationally known treatment centre for patients with intractable chronic pain. She is the Director of the program since its inception. She is also a senior investigator with the Krembil Neuroscience Centre and the Toronto Western Research Institute, full Professor in the Faculty of Medicine, University of Toronto, a founding member of the University of Toronto Centre for the Study of Pain. She is a proliferative clinician and scientist. Her research on

pain mechanisms, pain genetics, epidemiology and evidence-based medicine has been widely published in peer reviewed scientific journals. She has also delivered numerous lectures to scientific and lay audiences around the world.

Additionally, Mailis-Gagnon is a guideline developer and served as the co-chair of the Chronic Pain Task Force of the College of Physicians and Surgeons of Ontario, responsible

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"Today, I  
choose to  
dwell on the  
positive  
aspects of my  
life..."



David Harlow—Chairperson  
PNP

## Profile—David Harlow

IT IS A MIRACLE I'M ALIVE! In 1986, at the age of 37, my life changed forever while vacationing in Mexico when a rogue wave hit me from behind, breaking my neck in two places.

After being air-ambulated back to Ontario and spending three weeks in Sunnybrook Hospital, I was transferred to Lyndhurst for physical rehabilitation. With my head in a halo and my injuries at the same level as Christopher Reeves, I was discouraged from having any expectations for recovery.

Unable to find any positive reinforcement or encouragement from the medical profession regarding my condition and long term prognosis, I took responsibility for my recovery. Through a lot of hard work, determination, help from family and friends, and a belief that, with God's help I could recover, after 10 months at

Lyndhurst, I was able to accomplish the three goals I set out for myself upon arriving:

1. Hug my young children.
2. Pack my own tobacco pipe.
3. Walk out by myself.

One doctor was even annoyed because I had ruined his research paper!

After two more years of rehab, I returned to Mexico and stared down a giant wave similar to the one that had tried to end my life.

Today, I choose to dwell on the positive aspects of my life—my loving wife, family, and good friends. In addition to my management company, I enjoy time for volunteer work, blues music, good food, wine, cigars, and driving with the top down. Yes, I am still partially paralyzed and, among other conditions, suffer from neuro-

pathic pain, but it's a miracle I'm alive and I am grateful for every minute of it.

## Dr. Angela Mailis-Gagnon

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for the 2000 Evidence-Based Guidelines for the Management of Chronic Non Cancer Pain. She has continued to be instrumental in the generation of several other guidelines, including the National Opioid Use Guideline to be released late in 2009 in the country. She is member of many scientific societies and her pioneering work has been featured several times on television, radio and the press. Her most recent appearance was on Canada AM CTV on August 1, 2007 in regards to the impact of chronic pain in the country. She has authored a popular science book titled BEYOND PAIN (Viking Canada, released in May 2003 and re-printed January 2006), which was also released in the US in 2005. She has authored an educational booklet (Pocket Atlas of Neuropathic Pain Syndromes) for both health professionals and patients, which so far was distributed to 23,000 doctors throughout the country in 2006, and has another one in preparation. She is also the chair of ACTION ONTARIO, an advocacy organization of scientists and health professionals for patients who suffer from neuropathic pain (pain arising from injury to the nerves, the spinal cord or the brain). She has spearheaded the organization of a patient advocacy group associated with ACTION ONTARIO and has contributed with the assistance of her computer artist husband, to the group's unique website in terms of scientific content and 3 D animation ([www.actionontario.ca](http://www.actionontario.ca)).

On a personal front, Mailis Gagnon became resident of King Township in May 2005, after she left Toronto where she resided since 1978. She is married to a French Canadian 3D artist and has two sons from a previous marriage attending

university. She holds a black belt in Tae Kwon Do, trains several times per week in the gym, pursues currently a different form of martial arts (Russian Martial Art) and is an avid motorcycle rider, seen often to roam the country roads on her big Harley, alone or with her husband.

“She has authored a popular science book titled **BEYOND PAIN**”

**ACTION Ontario will host its second annual Symposium on Neuropathic Pain during National Pain Awareness Week**



*ACTION ONTARIO invites you to attend*

### Towards an Ontario Strategy *A symposium on neuropathic pain*

Neuropathic pain is the result of damage or disease to the nervous system. It has one face – that of suffering and distress – but its causes are many, including multiple sclerosis, diabetes, AIDS, cancer and nerve injuries.

Neuropathic pain affects more than one million Ontarians. Unfortunately, people suffering from neuropathic pain often have difficulty receiving proper diagnosis and appropriate treatment.

If these problems are to be addressed, Ontario must have a comprehensive strategy to deal with the many types of chronic pain, including neuropathic pain.

*Towards an Ontario Strategy*, a symposium being held during National Pain Awareness Week, will bring together patients, clinicians, researchers and other interested people to explore the possible shape an Ontario comprehensive pain strategy might take.

**When:** Tuesday, November 3, 2009  
1:00-4:30p.m.

**Where:** MaRS Auditorium  
101 College Street, Toronto

*Refreshments will be served following the event.  
For more information, and to RSVP, please e-mail [actionontarioadmin@gmail.com](mailto:actionontarioadmin@gmail.com).*

**Event Sponsored by:**





## ACTION Ontario Patient Advocacy Newsletter

8 Burgundy Trail  
Thornhill, ON  
L4J 8X5

For more information, please visit  
our website  
[www.actionontario.ca](http://www.actionontario.ca)  
E-mail: [email@actionontario.ca](mailto:email@actionontario.ca)

For People with Neuropathic Pain

Watch us Grow!  
Pass this newsletter along to  
family and friends you think  
might benefit.

### PNP Board Members:

ACTION Chairperson

**Dr. Angela Mailis-Gagnon, MD**  
Director, Comprehensive Pain Program.  
Toronto Western Hospital, Toronto.

**Dr. James Henry, Ph.D.**  
Scientific Director, DeGroote Institute for  
Pain Research.  
McMaster University, Hamilton.  
Executive committee member

**Dr. Larry M. Picard, MD, FRCP(C)**  
Diplomat - American Board of Psychia-  
try and Neurology

**Barry Sessle, MDS, Ph.D., DSc (hc), FRSC**  
Professor and Canada Research Chair,  
Faculty of Dentistry,  
University of Toronto,  
Past-President, Canadian Pain Society,  
Secretary & Executive Committee  
member.

**Dr. Judith Hunter, Ph.D**  
Professor, Dept. of Physical Therapy.  
University of Toronto.

**Dr. Philip Peng, MD**  
Anesthesiologist  
Dept of Anesthesia, University Health

Network,  
Wasser Pain Management Centre.

**Kianda Mauch, RN.**  
St. Michael's Hospital

**Dr. Tara Jeji, MD, MBA**  
Director, Ontario Neurotrauma Founda-  
tion

**Dr. Jennifer Stinson, RN, BSc, MSc, PhD.**  
Assistant Professor, Lawrence S.  
Bloomberg Faculty of Nursing,  
University of Toronto.

**David Harlow, Chairperson PNP**

**Janice Frampton, co-chair PNP**

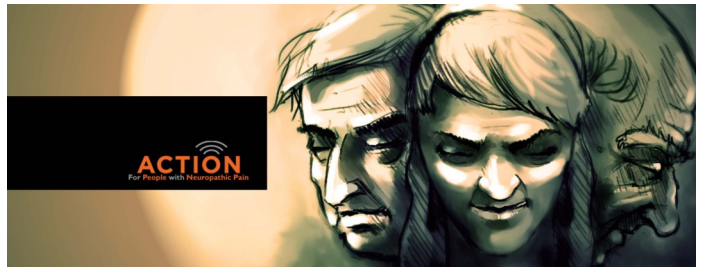
## History of ACTION Ontario

Launched in 2005, ACTION Ontario is an innovative not-for-profit organization. Its mandate is to advocate on behalf of patients with Neuropathic Pain (resulting from injury or disease of the nerves, the spinal cord or the brain), in order to secure better and faster access to pain therapies. We operate as a volunteer board comprised of doctors and other health care professionals from nursing, psychology, physical therapy and other disciplines. In addition to those working in the delivery of health care, the board is rounded out with the inclusion of patient representatives and scientists researching pain mechanisms. As volunteers with ACTION, each and every one of us is committed to improving the lives of people managing

with Neuropathic Pain.

Recent studies in the United Kingdom estimate that up to 8% of the total population may suffer from Neuropathic Pain, a number that is much higher than previously thought. If this is true for Canada, it would mean that close to 2.5 million Canadians may suffer from this condition, which dominates their every waking hour. 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 dollars annually with a broader impact on lost income and productivity, estimated to several billion dollars per year.

Neuropathic Pain is not well un-



derstood by either health care providers or lawmakers and, as a result, the condition is underfunded and under-treated in Ontario. ACTION Ontario intends to change this. We believe that greater public awareness of Neuropathic Pain will eventually result in the dedication of additional resources to its treatment as part of a more targeted, coordinated government response. In this way, we can hope for a better life for the many people who suffer from Neuropathic Pain.

ACTION Ontario is committed to working closely with different levels of government, researchers, physicians and other health-care providers in order to achieve our goals of improved access to pain therapies. Please join with us to build a better future for those with Neuropathic Pain.