



OUCH

Optimism and Understanding Creates Hope

Volume 1 Issue 2 February 2010

Kids Get Neuropathic Pain Too!

By: Jennifer Stinson

Neuropathic pain in children has an impact on all aspects of their lives. In attempting to protect the painful parts of their bodies, such as an arm or leg, a disability problem may also arise in some children. They may avoid exercising or playing sports, stop going to school, and withdraw from social activities. They can also have trouble sleeping, suffer from anxiety and/or depression, and may even have strained relationships with family and friends. If activities and socialization stop for long periods of time, re-integration becomes more difficult and the child becomes isolated and lonely.

A common type of neuropathic pain in children is Complex Regional Pain Syndrome (CRPS). Children with



Jennifer Stinson, RN, PhD

cancer also experience neuropathic pain, either due to the cancer treatment (chemotherapy or radiotherapy) or the underlying cancer itself (for example, due to the tumour impinging on a spinal nerve root).

Nerve pain is often described as burning, stabbing or shooting and may be spontaneous or evoke (that is, having a

trigger factor such as touch or change in temperature). It can also have sensory (pain on light touch), motor (tremors, muscle wasting or atrophy, spasms) and autonomic disturbances (colour and temperature changes, excessive sweating).

What is the best treatment for neuropathic pain in children?

There are a limited number of chronic pain services for children in Canada most of which are located in large urban centers. The key to the success in the management of neuropathic pain in children is adopting a multi-disciplinary, multi-modal (pharmacology, psychology and physical therapies also referred to as the 3 P's) rehabilitation approach to the individual child. Chronic pain

(Continued on page 2)

Youthful Determination Overcomes Adversity

By: Shanelle Rock

In 2003, at the age of 11, I began experiencing back pain. I was diagnosed with a moderate case of scoliosis, a congenital spinal defect where the upper half of the spine curves in one direction and the lower in another. My abnormality wasn't severe enough to receive any cor-

rective treatment so I relied on physiotherapy twice a week and the occasional Tylenol to cope with the pain and muscle spasms. Despite the pain, I forced myself to remain both academically involved and physically active playing on my school's volleyball team.

When I began menstruating one year later everything changed. The pain that came with it was overwhelmingly agonizing. One afternoon, a teacher found me crumpled on the school floor outside my locker unable to walk because of the pain and my brother had to come and carry me home from

(Continued on page 5)

Did You Know?

ACTION Ontario is committed to the journey of providing the best care possible for all people with chronic pain, especially neuropathic pain, in the province of Ontario. As part of this on-going commitment ACTION Ontario will be hosting a third pain symposium on November 2nd, 2010.

For more information on upcoming events of other organizations affiliated with ACTION Ontario please follow the links provided on our website.

Inside this issue:

Editor's Message 3

Profile—Frances Lau 3

Pain Symposium Hits a Personal Nerve 4

Profile — Janice Frampton 6

History of ACTION 6

ACTION Ontario Membership Form 7

Neuropathic Pain and Children

(Continued from page 1)

teams including anaesthetists, neurologists, psychiatrists, nurses, psychologists and physical therapists now may also include complementary and alternative therapists such as acupuncturists and/or massage therapists.

-For a list of dedicated paediatric chronic pain teams see pain resource centre on the Canadian Pain Coalition's website: (<http://prc.canadianpaincoalition.ca>).

The 3 P's

Pharmacological Therapies

Pharmacological interventions are of benefit for certain types of chronic pain such as nerve pain, although research involving children is extremely limited. Few medications are specifically created or licensed for use in children, especially for the treatment of chronic pain. The clinical use of these medications in children is taken from the research evidence in adults with chronic pain.

Pain medications should be tailored to your child's needs. Medications may include

“Chronic pain often leads children to avoid physical activities due to fear of re-injury”

acetaminophen, ibuprofen and or opioids.

However, the best medications for neuropathic pain in both children and adults are anticonvulsants (such as Gabapentin and pregabalin) and tricyclic antidepressants (amitriptyline, nortriptyline, desipramine). Only pregabalin is formally approved by Health Canada for use in treating adult neuropathic pain, gabapentin is not. However, both these medications are used for the management of neuropathic pain in both children and grownups.

Cannabinoids have been found to be effective in treatment of neuropathic pain related to multiple sclerosis in adults. However, there is limited research on their use in children with neuropathic pain. While opioids, have been shown to have some efficacy in the management of adult neuropathic pain; there is relatively little clinical or laboratory data on the use of opioids in the management of chronic pain in children.

Physical Therapies

Chronic pain often leads children to avoid physical activities due to fear of re-injury or because it makes their pain worse. Lack of muscle use leads to loss of muscle strength, flexibility, endurance and overall de-conditioning. Therefore, physical therapy is an integral component, and in certain instances, for example CRPS, the cornerstone of treatment for children with neuropathic pain. Physiother-



Chronic Pain Team at SickKids

apy is usually administered on an outpatient basis with the ultimate goal of teaching the child to continue the program at home. Regular exercise (20 minutes three times per week) can also help improve sleep, mood, self-esteem and energy levels. Treatment plans can also include massage, thermal (heat and cold) and sensory stimulation (desensitization, transcutaneous electrical nerve stimulation or TENS)

Psychological Therapies

Treatment usually includes psychological or psychiatry to help children and teens understand the factors that can intensify pain and prolong disability. Treatment may include educational counseling, relaxation therapy (imagery, distraction and relaxation), behavioural modification, self-management and life-coping techniques, and cognitive pain control strategies.

FOOTNOTE: Non-invasive therapies (pharmacological, physical and psychological, in short the 3 Ps) are the mainstay of treatment of

paediatric chronic pain conditions. However, certain types of injectable medications (the medical term is intravenous regional analgesia with single regional blocks or continuous lumbar sympathetic blocks) can be a useful adjunct in children with CRPS who do not respond to treatment with non-invasive therapies.

For more information chronic pain in children see the following resources:

Pain resource centre on Aboutkidshealth website at the Hospital for Sick Children
www.aboutkidshealth.ca/Pain

A Child in Pain: How to Help, What to Do

by Leora Kuttner
Paperback: 288 pages
Publisher: Hartley & Marks Publishers (1996 reprinted 2006)
ISBN: 0881791288

Submitted by:

Jennifer Stinson, RN, PhD
Scientist and nurse practitioner,
Chronic Pain Program
The Hospital for Sick Children
ACTION Ontario Board Member

Editor's Message

Dear Readers,

Welcome to the second edition of OUCH. I would like to take this opportunity to welcome all our members to Action PNP and look forward to your on-going support and feedback. In this edition, we are highlighting the impact of neuropathic pain on children – I would like to thank Jennifer Stinson, Hospital for Sick Kids, Toronto and Shanelle Rock, a teenage patient, for their contributions. Each new edition of OUCH will continue

to profile the dedicated members of the ACTION organization and members of the neuropathic pain community.

Heartfelt congratulations go out to all the organizers, panelists, participants and attendees of the ACTION Ontario Pain Symposium, "Towards an Ontario Strategy" held in November. Because of everyone's hard work and on-going support our collective voice is starting to resonate within the halls of power.

As part of our spring member-



ship initiative, ACTION PNP is challenging each and every one of our readers to "spread the word" by forwarding on a copy of OUCH to as many family, friends and pain sufferers, to increase our visibility within Ontario. There is no cost to joining Action PNP, so in an effort to reach out to more people, a membership form is included with this edi-

tion of OUCH. There is also a membership form available at the ACTION ONTARIO website www.actionontario.ca.

Pass it around; fill it out and be part of what we can achieve!

Please feel free to contact me at email@actionontario.ca with any topics you would like us to address in future editions.

As Always,
Janice Frampton
Editor

Profile—Frances Lau



Frances Lau
Coordinator
ACTION Ontario/PNP

"I discovered a new adventure and journey in my life when I started working with ACTION Ontario: My dedication to help others and the challenge of building an advocacy group. It is different than my corporate life, but the personal reward is tremendous!"

Frances Lau came to this new journey through a long road of learning, both in life and academic experience. She was born in the Pearl of the Orient – Hong Kong, to two selfless people who risked their own well being by opening their home to Chinese refugees escaping political persecution in the 60's. By the age of nine, Frances's job was to take the refugees for medical treatment after they had swum in the South China Sea for 10 hours.

Through this experience, Frances saw firsthand what it was like to advocate for the people who have no voice and help others to independence.

Frances left home in 1974 in search of furthering herself academically and travelled 35

hours by plane to Windsor, Ontario where she enrolled in F. J. Brennan High School.

After graduating with a degree in Computer Science she began working as a data processing instructor at St. Clair College of Applied Arts & Technology. Her desire for self improvement and knowledge lead her into the progressive field of information technology in many organizations, from consumer goods, health and, ultimately, the health care industry.

She later realized her true passion was to integrate diverse interest groups to deliver results and this brought her to ACTION Ontario in 2006. Following the launch of the PNP group, Frances knew she had finally found an advocacy home for herself. Her understanding of the dedication and determination for the people and patients who come with their life struggles and strive to build a better life was a perfect fit.

Today, Frances is an integral part of the combined ACTION

groups; her unique combination of passion, organizational skills and dedication are the backbone for the organizations. In 2008 and 2009 ACTION Ontario hosted two successful Neuropathic Pain Symposiums to introduce Ontarians to Neuropathic pain and the need for advocacy. Frances Lau was part of a silent driving force behind this success.

Frances's two best projects in her life remain her children, Jennifer and Ryan. She is proud of their high social conscience and continued acts of kindness towards others. Jennifer does volunteer work with "Road to Care," a charity that aids Ugandan women with cervical cancer and Ryan was a volunteer at the City School.

Frances continues to embrace the future outcome of ACTION Ontario: a Comprehensive Pain Strategy in Ontario that gives patients the voice in pain management they deserve in order to improve their quality of life.

"Frances knew she had finally found an advocacy home for herself"

Pain Symposium Touches a Personal Nerve

Today is a good day for Kim Nelson and her daughter Carley. For the first time since Carley's accidents, Kim is sure nobody will walk up to her daughter and ask how her "pain thing" is. Today Kim knows Carley is among friends, people who not only understand exactly what her "pain thing" is, but will relate to her daughter's story of misdiagnosis, lack of treatment, ridicule and yes, of course, pain. Today, Kim and Carley are two of the panelists willing to share their story of struggle for a diagnosis of neuropathic pain at the November 3rd symposium hosted by ACTION Ontario.

During the symposium entitled "Towards an Ontario Strategy," Carley, and three other patient panellists, told their heart breaking stories. The predominant theme of the lack of provincial structure for the treatment of chronic pain was repeated time after time before a diverse audience of more than 130 people made

up of patients, physicians, health care providers, pain researchers and other stakeholders.

The patients told of their difficulty with getting an accurate diagnosis and pointed to a serious lack of knowledge about chronic pain amongst primary care physicians. They also relayed stories of the problems with accessing and paying for medication or for all sorts of other treatments already available in other provinces ... and, until today, the lack of hope.

By discussing the success of other provinces in managing chronic pain, Dr. Angela Mailis-Gagnon, chair of ACTION Ontario, drew attention to the human need for a comprehensive pain strategy in the province of Ontario. Such a strategy will address pain all the way from the family doctor's office to specialty pain clinics, and will also provide patients with self-management tools.

"Patients in the community face what I call 'spaghetti care,'" says Dr. Mailis-Gagnon. "The tangled noodles represent the uncoordinated, imbalanced and broken communication and care our patients face every day."

The audience also heard how two important chronic diseases, diabetes and stroke, have been able to successfully develop comprehensive strategies of care within Ontario.

With the use of interactive electronic "clickers" the audience shared its views on both the problems and possible solutions towards achieving a comprehensive chronic pain strategy in Ontario. Many of the problems brought forward by the audience were common to those expressed by the four panellists and the solutions suggested provided some important direction for ACTION Ontario.

Dr. Mailis-Gagnon acknowledged that although "the solution needs to be one that involves coordination and community care, ACTION Ontario cannot do it alone." She went on to say, "To achieve our goals we must build a coalition by involving well-recognized, credible partners."

For patients like Carley, the very discussion of these topics is cause for hope. "It took so long for anyone to even believe me when I told them I was in pain," she said. "It's important to me that the message gets out there and people understand what living with neuropathic pain is like."



Carley and Kim Nelson
Patient Panellists,
ACTION Ontario Pain Symposium

"It took so long for anyone to even believe me when I told them I was in pain."
Carley Nelson



Dr. Angela Mailis-Gagnon
Chair, ACTION Ontario

"Patients in the community face what I call 'spaghetti care.'"
Dr. Mailis-Gagnon



Dr. Angela Mailis-Gagnon and Patient Panellists
ACTION Ontario November 2009 Pain Symposium
"Towards an Ontario Strategy"

Determination Conquers Adversity

(Continued from page 1)

school. My bedroom became my sanctuary, a heating pad my best friend and different combinations of Tylenol, Advil and prescription medications my helpers in the battle against pain and migraines. I was diagnosed with endometriosis, a disorder of the female reproductive system where the cells of the uterine lining grow outside of the uterus and attach to the surrounding organs.

Instead of going to school, playing volleyball and socializing with my friends, I had succumbed to treating my pain with various medications and secluding myself from the world outside in my room. I felt overwhelmingly lonely even when I did go to school because of the constant questions about my health that I could never answer.

Over the next three years, I found a way to dull my physical pain with the help of Naproxen and extra-strength Tylenol. Gradually, the emotional stress of my physical pain combined with struggles at school, difficulties at home, and keeping up the well practiced façade that I was getting better took their toll on my mind. Soon I began to daydream about ways to end it all.

My road to recovery began when the principal found me crying in a little used stairwell of the school during one of the moments where my façade fell to pieces. I am forever grateful for her guidance in helping me find

a therapist who led me to my current social worker.

Through Cognitive Behavioural Therapy, I learned to use my unwavering passion for music and talent for playing the flute as healthy and safe outlets for my emotions. I also used breathing techniques to clear my mind long enough to think of ways to help myself which was impossible for me to do before.

At 17, I began experiencing new pain symptoms which I didn't understand. After being referred to the Pain Clinic at Sick Kid's I was diagnosed with neuropathic pelvic pain from the continuous stress being placed on my pelvis from my endometriosis. So now my nerves are in pain even if there is nothing painful happening to my body at the time.

I learned there are three main ways to treat neuropathic pain; pharmacologically, physically and psychologically.

When I tried Gabapentin as part of a drug trial it did not agree with my body and left me nervous to try any other medications so I decided to focus on the physical and psychological routes instead.

Because of some of the side effects I was once again forced to stay in bed for weeks and wait for my symptoms go away. I found myself slowly falling back into depression because of my inability to attend school and the fact I was no longer at the top of my class. Being

bedridden plays tricks on your mind and the world becomes a very small, lonely, isolated place.

After awhile of watching the world pass me by I realized the only person who could help me break the isolation was me so I began to take steps to move forward.

Now that I have turned 18, I've taken charge of my life. I went to summer school, repeated my two worst subjects and bumped my overall average up from 76% to 80%! I decided to take a year off school and get control of both my mental and physical health.

In order to keep myself occupied I started working as a volunteer in two kindergarten classes. This opportunity proved to reinforce my desire to become an elementary school teacher and I just received confirmation of my acceptance to my ideal school – the University of Windsor.

Through physical therapy exercises, yoga and Pilates, I've started to regain strength in my body and by continuing to go out with my friends I maintain a healthy outlook on my youth.

I once thought that since my body had betrayed me I would never lead a "normal" life. Since finding the people willing and able to offer me the appropriate tools I have now found the control I thought I had lost so many years ago.



Shanelle Rock

Advice to Others:

1. Stay active. Staying in bed for more than a day leads to helplessness and depression.
2. Find a support person who understands your health problems you can relate to. Mutual communication is important.
3. Set a goal and stick to it. You'll be proud of yourself when your dream becomes reality.
4. Don't let your medical condition define you. Your condition is a part of you but you don't have to let it control you.

"I have now found the control I thought I had lost so many years ago."



Janice Frampton
Co-Chair ACTION PNP

Since childhood I have lived with the pain of thousands of sharp knives stabbing me in the right side of my abdomen back and leg. Throughout my lifetime I would double over in agony during bowel movements, at times even vomiting. I always knew there was something "abnormal" happening in my body but nobody in the medical profession seemed to want to look beyond the obvious so I was labelled a "Drama Queen" and left to deal with the pain by myself.

Instead, I was diagnosed with everything from sciatica to mental disorders and even alcoholic neuropathy.

Profile—Janice Frampton

For the first 46 years of my life I lived with untreated neuropathic pain because of 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. The condition is degenerative and is closely linked to spina bifida.

For years I tried to outrun the pain and torment that overcame me and my body until finally I could run no more. By October of 2002, I was a broken human being near death and no closer to a medical solution for the cause of my physical pain.

The road to my diagnosis finally began one night in October 2003 when I realized I hadn't felt a thing after scalding myself in the bath tub from the waist down. The lower half of my body was completely

numb. From there an MRI of my back was ordered and the Tethered Spinal Cord Syndrome was discovered.

From December of 2004 to June 2006 I underwent five spinal surgeries, the first was to untether the cord and the subsequent surgeries were to correct complications that arose from the initial surgery.

While I still suffer from neuropathic pain, I now know why – this knowledge makes all the difference in the world to me. It has allowed me to come to terms with my limitations and I no longer beat myself up for things that were beyond my control.

I am a very fortunate person. Since meeting Dr. Mailis and becoming involved with ACTION PNP I've had the opportunity of helping others through their journey of dealing with neuropathic pain and of self discovery. I am

surrounded by a very supportive and loving husband, the miracle of four beautiful daughters and a cast and crew of family, friends and physicians that challenge me on all fronts and make it all worthwhile. I am a survivor that beat the odds and I am grateful.

"While I still suffer from neuropathic pain, I now know why-this knowledge makes all the difference in the world to me."

History of ACTION PNP

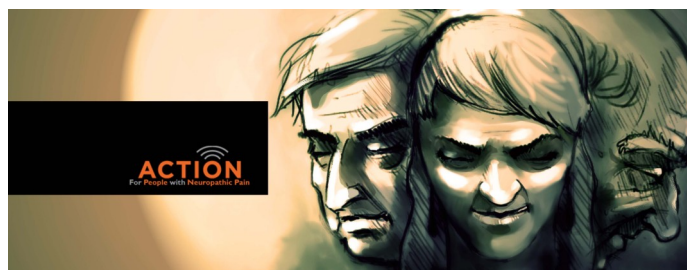
Approximately two years after its inception in 2005 the ACTION Ontario board realized it needed not "a" voice, but "many" voices to strengthen its mandate and represent its concerns to government and the public at large. These voices had to be the very people the Action Ontario board were trying to help – the patients.

In their quest for patient volunteer representation, the Action Ontario board sought the help of their fellow physicians and following these physician's recommendations the first meeting of ACTION PNP (People with Neuropathic

Pain) was held in the dining room of Trinity College at the University of Toronto in February 2007. The initial mandate of the group was to establish its role within the larger framework of ACTION Ontario in promoting the awareness of Neuropathic pain.

In May 2007, ACTION PNP proudly unveiled its banner for the first time in Ottawa after it was invited to participate at the Neuro Modulation Conference.

Since that time, ACTION PNP, under the umbrella of ACTION Ontario, has established itself in the advocacy



and pain community as it continues to highlight the need for education, openness and understanding for people suffering with neuropathic pain.

Action PNP works closely with other advocacy groups, such as diabetes, has produced patient videos, been featured in newspaper, magazine and television articles and participated in government sponsored initiatives.

ACTION PNP, together with ACTION Ontario, has also co-hosted two very successful Neuropathic Pain Symposiums as it strives to fulfill its mandate of bringing more awareness to the government and people of Ontario as it works towards an "official" Ontario Strategy on neuropathic pain.

For more information please visit

www.actionontario.ca



MEMBERSHIP APPLICATION FORM

ACTION Ontario People with Neuropathic Pain (PNP)

I wish to join ACTION Ontario PNP.

ACTION Ontario is an innovative not-for-profit organization whose 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.. As a member of ACTION PNP, each and every one of us is committed to improving the lives of people with Neuropathic Pain.

Type of Membership: Regular* or **Associate***

**"Regular" refers to a person who has been diagnosed with Neuropathic pain. "Associate" refers individuals who wish to support the work of ACTION Ontario PNP*

Name: _____ **Gender:** M F
Surname Given Name Initial

Address: _____

City: _____ **Prov:** _____ **Postal Code:** _____

Phone: () ____ - ____ home () ____ - ____ work () ____ - ____ cell

(Optional) Age Group: 18-35 36-55 55+

Please **add me to ACTION Ontario PNP's E-mail distribution list** to receive updates and relevant information from ACTION:

Yes: ____ **Email:** _____

There is no charge for membership. The ACTION Ontario welcomes all the help which our members can offer in the way of volunteer activities.

Please **mail** the completed membership form to:

ACTION Ontario, 8 Burgundy Trail, Vaughan, Ontario. L4J 8X5

Or email ACTION Ontario PNP at email@actionontario.ca

Privacy Statement: the information collected in this form is for ACTION PNP membership only, and will not be shared with other parties for commercial or other usage.