



OUCH

Optimism and Understanding Creates Hope

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Putting The Patient Voice First

ACTION Ontario declared 2010 as the unofficial "Year of The Patient's Input." Throughout the year ACTION Ontario was at the forefront of this movement, always putting the patient voice first and foremost. This "voice" culminated in ACTION Ontario's annual Symposium held on November 7th during National Pain Awareness Week. The title for the 2010 Symposium was "Patient Input for System Change."

As always, the 2010 symposium included a patient panel who told their life altering stories of a system which not only does not listen to patient's and their symptoms but is incapable of administering to the needs of chronic neuropathic pain

sufferers in the province of Ontario.

The patient panel told of 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 panellist, Mr. 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 panellist, 17-year-old Veronica Dunlop,

who suffers with Complex Regional Pain Syndrome, would like to see a clinic such as the one in Philadelphia where she is headed, become available for all young Canadians to attend. While recognizing the expense of these clinics she says, "Surely seven years worth of appointments with specialists plus many x-rays, ultrasounds, MRI's and bones scans costs even more."

They 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.

What made this year's symposium even more unique was the inclusion of the caregiver to the patient panel. Caregivers are not only on

Did You Know?

It is income tax time. If your main source of income is from a private disability pension fund or Canada Pension Plan Disability, be aware of all the income tax deductions available to you. The Disability Tax Credit is available to all persons "who have a severe and prolonged impairment in physical or mental functions." This form must be filled out by a physician for qualification and verification. If you are not sure what deductions you qualify for, it is best to speak to a chartered accountant.



Patients, participants, caregivers and healthcare professionals mingle in the lobby of the MaRs Centre during the 2010 Symposium

(Continued on page 6)

Inside this issue:

Profile—Bill Daya 2

Dear Readers 3

Introducing... 3

Queen's Park Day 4

Pain in Older Persons 4

Bill 101 Advocacy 5

Profile—Julie Feldman 6

Membership Form 7

Profile—Bill Daya

The year 2005 proved to be a year of decision for Pharmacist/Owner Bill Daya. After 20 years of operating under the banner of Guardian Drugs, Mr. Daya realized he did not want to lose the autonomy and uniqueness of his individual store. He decided to break away becoming a rare and dying breed in the age of big box store pharmacies – the independent pharmacist.

"For me, it is about business adjusting to the local community," says Mr. Daya. "Not the other way around."

Born in Johannesburg, South Africa, Mr. Daya grew up under the oppressive Apartheid regime. At the age of 12 he had his first multiracial experience when he was sent to a boarding school in Swaziland to complete his O levels for four years. As education was sorely lacking in this part of the world, his parents sent him to England in 1969 to complete his A levels, the North American equivalent of High School.

Once in England the world was his oyster from an

educational perspective and he always knew he wanted to be in the medical field in some aspect. As a young boy in Johannesburg he was "greatly impacted by the incredible knowledge and compounding skills" of a local pharmacist so he chose Pharmacy as his own calling.

After receiving his Pharmacy degree from the University of Sussex in Brighton, Mr. Daya spent a year as an apprentice at the hospital in Worthing, Sussex. In 1976 he moved to Toronto where his brother resided and he had already spent some time.

After moving around and working at a number of pharmacies in different locations in the GTA, he eventually purchased Fairport Guardian Drugs in Pickering in 1985.

As an independent pharmacist/owner under the Guardian banner, for many years Mr. Daya established himself as a knowledgeable, caring pharmacist. If there was a change in your prescription or a sudden influx of medication, Bill Daya would and still will call to find out why. He is the unsung hero in a community surrounded by the big box mentality with a high turnover at the pharmacy counter.

Over the years Mr. Daya has seen many changes to his profession. Most significantly the introduction of Bill 102, "The Transparent Drug System For Patients Act," passed in 2006. While Mr. Daya agrees the system did need some reform, he sees the downside of the Act to patients on a daily basis.

"Everyday at least five drugs aren't available for patients from the manufacturer." He says. "These are old drugs, blood pressure medication that has been around for 35 years. It used to be the manufacturers would take production money out of the reserve funds but since this isn't there anymore we (the pharmacists) have to scramble to find replacements, sometimes at a higher cost to the patient."

The introduction of Bill 102 also spells the end of the independent pharmacist. "I should be at a stage in my life where I don't have to worry about my financial survival. Bill 102 turned all that around." Mr. Daya admits Pharmacists have been "too timid for too long" and it is time for them to stand up for themselves in the face of adverse legislation that hurts not only them but the public at large. "Patients just won't get quality service. And that will become the norm."

Another big change Mr. Daya has encountered in his profession is the widely accepted use of narcotics. He is hoping that the introduction of Bill 101 will help to "break down the volume of flow of narcotics." He believes narcotics have become too easily acceptable and too readily available on the one hand but also believes doctors must do their jobs by assessing and prescribing the medications properly when necessary.

The biggest impact on the pharmacist today, in his opinion, is Bureaucracy, both from private insurance companies and the government.

"Pharmacists, like doctors,



Pharmacist and Action Ontario Board Member Bill Daya

have become administrators." He says. "We spend too much time sorting out people's insurance plans and not enough time being health-care providers."

With the introduction of Bill 101, and the influx of new medication for the control of neuropathic pain onto the market, Mr. Daya was only too happy to lend his expertise to ACTION Ontario. He recently became a member of the ACTION Board.

Mr. Daya lives in Pickering with his wife Mina. He has two daughters and two grandchildren. He enjoys golf and sits on the Board of the Ajax Flying Club for remote control planes based out of Markham.

Despite the many changes in Pharmacy itself, Mr. Daya is a fixture behind the counter of his store administering to his many dedicated clients. Because, as he says with his characteristic self deprecating grin, "I love my profession and I still love going to the pharmacy."

For those who count on Mr. Daya on a daily basis, they are delighted he does.

www.actionontario.ca

"Patients just won't get quality service. And that will become the norm."

Editor's Message

Dear Readers,

If 2010 was the unofficial year of the patient's input, 2011 promises to be the year of the patient. With two elections on the horizon, voters can expect an array of promises from candidates of all parties with regards to healthcare. Be smart and be careful about where you choose to mark your vote. Get in contact with your candidates and ask the tough questions about where they stand on public policy on healthcare. This is your health, your healthcare and your future.

The patient voice is clearly an important one and having an impact. Just this past month members of ACTION were personally invited to participate in the inaugural "Patients

Association of Canada" conference, an organization dedicated to "Improving the Patient Experience." Next month ACTION will be participating in another conference to dialogue about Chronic Pain. As well Dr. Angela Mailis-Gagnon has been invited to sit on a six member expert panel on the future of a chronic pain strategy in the province of Ontario. ACTION will be asking for patient participation in the process as it moves into the public forum. Who knows best where the system fails if not the ones who use it on a day to day basis – the patients.

After two very successful years as Chairperson of ACTION PNP, David Harlow has stepped down from the position. We wish David every



success in all his future endeavours. As well, Cindy Harding has left her position on the Steering Committee and again, we wish her much success.

As the saying goes, when one door closes, another door opens and so it is with ACTION. It is my great honour and privilege to announce my own appointment as the new Chairperson of ACTION PNP with Ms. Maxine Bergman as the new Co-Chair. We are also excited and honoured to announce three new members to our Steering Committee, Ms. Anita Geerts, Ms. Ann Tuzi and Dr. Ramesh Zacharias.

We look forward to the new energy and enthusiasm these appointments bring to the committee.

Thank you to those who contributed to this latest edition, Dr. Ramesh Zacharias, Rachel Weisz, Bill Daya, Julie Feldman and Laura Greer. I would like to hear from **YOU** at editor.ouch@gmail.com. Tell me about the topics that are important to you and your health/pain issues. You can now read OUCH online at www.actionontario.ca!

For information on membership please contact: action-ontario@rogers.com

As Always
Janice Frampton
Editor

INTRODUCING.....

The ACTION PNP Steering Committee would like to take this opportunity to welcome our newest members and introduce them to you.

Anita Geerts

Anita Geerts is a sales executive with an IT firm. Her experience with neuropathic pain is through her father, Will—she accompanied him on the quest to get proper medical diagnosis and treatment for his neuropathic pain. The quest led them to meeting 40 doctors before getting full diagnosis and treatment through the clinic of Dr. Angela Mailis-Gagnon. Now her father is able to lead a happy and

productive and independent lifestyle once again. Anita believes it is time to make management of severe pain available to all Canadians.

Ann Tuzi

Ann Tuzi worked at the Hudson Bay Company for 25 years, the last two years as store manager, before becoming ill with Burkett's Lymphoma in May 2002. In October of 2003 she developed shingles and by the time she was referred to a pain clinic at the Princess Margaret Hospital, it was "too late," she has developed Post Herpetic Neuropathy. Unable to work because of the severe pain, a

once joyous and bubbly Ann fell into a deep depression. After being introduced to ACTION Ontario by her doctor, Dr. Watson, Ann decided it was time to get involved and share her experience with other people in the same situation.

Ramesh Zacharias MD FRCS DAAPM CMD

Dr Zacharias graduated with his Doctorate of Medicine from the University of Western Ontario in 1980. He obtained his Fellowship in General Surgery in 1987. From 1983-2009 he was the CEO of Med-Emerg Inc, Canada's largest physician staffing company. For 20 years

he worked as an Emergency Room Physician. Since 2002 he has served as Medical Director of Long Term Care facilities. He established a community based Chronic Pain Practice in 2004 where he continues to work in an inter-disciplinary pain practice. He is the Director of Clinical Services for the Schlegel Villages that manages 14 LTC and retirement homes across Ontario. In 2010 he was appointed Assistant Clinical Professor (Adjunct) in the Department of Anesthesia McMaster University. He has a special interest in Neuropathic Pain as he suffers from the symptoms as a result of having diabetes for over 20 years.

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ACTION Ontario Hosts 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 Bill 101, the *Narcotics Safety and Awareness Act*, which could limit access to narcotics in the province of Ontario.

Throughout the day, a number of small groups comprised of ACTION Ontario Board members and PNP members were able to have individual meetings with several members of the Ontario Legislature or their representatives. As an immediate result we had ex-



Dr. Angela Mailis-Gagnon, PNP Co-Chair Janice Frampton and Health Minister Deb Matthews at ACTION's Queen's Park Day

pressions of sincere understanding and compassion. As well, promises of actual assistance in our quest to raise awareness about chronic pain and establishment of a comprehensive pain strategy for the province of Ontario.

At noon, 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 for solutions to the problems we are coping with. As well, the very moving speech from ACTION PNP's Co-Chair, Janice Frampton, had a noticeable impact on everyone in the room. We also heard encouraging words from Deb Matthews, the Minister of Health and Long-Term Care, as well as from both opposition health critics: Christine Elliott (PC), MPP for Whitby-Oshawa and France Gélinas (NDP), MPP for Nickel Belt.

ACTION Ontario can be proud of having raised our profile — and the need for a comprehensive pain strategy — during a successful Queen's Park Day.

www.actionontario.ca

Persistent Pain in Older Persons

By: Dr. Ramesh Zacharias

Albert Schweitzer once said: "The purpose of human life is to serve, to show compassion and to help others."

Epidemiological studies show that prevalence of persistent pain often exceeds 50% of community dwelling older persons and up to 80% of nursing home residents. Gibson, SJ Expert Review of Neurotherapeutics. 7(6): 627-35, 2007 June.

Consequences of untreated pain include depression/social isolation, suffering, sleep disturbance behavioral problems, anorexia, and weight loss. In

addition the elderly suffer deconditioning and increased falls often due to under treated pain.

It has been said that pain is something that happens to a body, suffering is something that happens to a person.

Assessment of pain in older persons poses significant challenges because of the high prevalence of co morbid conditions. This necessitates a comprehensive assessment of pain that involves consideration of the medical, psychological, cognitive, neuropsychological and behavioral factors. The assessment should

evaluate the functional limitations (effects on activities of daily living including sleep, mobility and appetite), psychosocial function (mood, interpersonal interactions, fear/anxiety behavior), and cognitive function (i.e. delirium or dementia or patient's beliefs about pain). It is essential that the assessment be interdisciplinary and that collaboration be mandatory when developing a treatment plan. Pain is both situation and context dependent. Integrated care should include treatment goals for both pain relief and improved function, not just pain relief. The ideal

treatment approach should include: Physical Therapies, addressing Psychological Issues and Medical Approaches including Pharmacological options and possibly Interventional Treatments. In addition the possible role of Complementary and Alternative Medicines (CAM) and the role of allied health professionals should be considered. Medications are only one approach to treating pain. The pain care plan should incorporate the following elements:

(Continued on page 5)

ACTION Ontario Leads the Way on Bill 101 Advocacy

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. As we know, people living with chronic pain often use opioids (narcotics) to help manage their pain, so when the government decided to move ahead with this legislation, ACTION knew it had to use this opportunity to stress the need for a chronic pain strategy for Ontario.

When Bill 101 was first introduced, not many concerns were raised about it publicly. However, it soon became apparent that patients with chronic pain could be ad-

versely affected by the introduction of the Bill if it were left to stand as is. One of ACTION's key goals was to ensure that chronic pain patients who needed prescription narcotics to manage their pain

of a strategy to deal with chronic pain. Now however it is very much a top issue at Queen's Park because ACTION was able to show the government that in order to deal with the opioid crisis in

raised in the legislature by all political parties, culminating with 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.

did not have their access limited with the introduction of the legislation.

The success of ACTION's advocacy initiatives soon became evident. Before we began our advocacy campaign this fall, very few spoke

the province of Ontario it must first address the issue of chronic pain. Throughout the course of the debate on Bill 101, which was passed into law at the end of November, discussion of the need for a chronic pain strategy was

ACTION Ontario has made great strides forward this past year and we should be proud of our success. It is important that we allow our success from the past year to deepen our determination to see a comprehensive pain strategy introduced in Ontario. As a group, we need to ensure the patient voice is heard. We

need to continue to engage with government so that the needs of chronic pain patients are addressed instead of ignored.



Pain in Older Persons

(Continued from page 4)

*Underlying causes identified and where possible addressed to reduce impact on symptoms

*The desired level of pain reduction or acceptable level of pain

*Patient-centered functional outcomes (eg., the ability to participate in activities, visiting with families, ambulation and sleeping through the night)

*Frequency with which the patient's progress and response to attempted pain

management need to be monitored, and who will do the monitoring.

*Potential adverse effects of treatments and the recommended frequency of monitoring for those effects.

JM Barrie the Scottish writer once said: Life is a long lesson in humility. Managing Persistent Pain in Older Persons is a journey that requires we learn from each other as well from our successes and failures. A society or more specifically a health profession will ultimately be judged by how it

treats those who are most vulnerable; such is the predicament of those with persistent pain.



Ramesh Zacharias MD FRCS DAAPM CMD

Medical Director: Village of Erin Meadows LTC

It has been said that pain is something that happens to a body, suffering is something that happens to a person.

Profile—Julie Feldman

Thirteen years ago, at the age of 33 I was shocked when I received the diagnosis of oral cancer. I had been experiencing great discomfort that required me to take regular amounts of extra strength pain relief medication throughout the day, but was truly unprepared for a diagnosis of this magnitude. Thankfully, after treatment, I recovered successfully.

Five years later after eating my dinner, I began to play with my little toy poodle Ruby on the living room floor. While on my hands and knees I inadvertently swung my neck to the left side a little too energetically, and immediately felt like I was possessed. The muscle in my neck was swaying back and forth vigorously like a rubber band. The pain from this neck spasm was relentless,

Dealing with persistent pain has been the biggest challenge of my life.

and still is, constantly with me 24/7.

At first the doctors thought the pain from the spasm could have been triggered by an allergy. Unfortunately, this was not the case. After four years of physiotherapy and three years of escalated pain I was eventually forced to forfeit a thriving career as a Learning Consultant.

As the pain and spasm continued without relief, I ultimately became bedridden, was unable to walk, eat or speak, or travel due to my hypersensitivity to changes in the road elevation. The simple act of being a passenger or driving a car caused my throat to experience choking sensations.

For five very long years I consulted eight different doctors as I sought relief for the pain that gripped my neck and had taken over my life. Finally, almost three years ago, I was referred to the clinic of Dr. Angela Mailis-Gagnon. It was she who provided the diagnosis of neuropathic pain. Through Dr. Mailis I became aware of the advocacy work of ACTION Ontario/PNP and

attempted to look beyond my own physical pain in order to help contribute to the cause of Action Ontario.

As a member of the ACTION PNP Steering Committee we are encouraged to write our profiles in an effort to share our experiences with our fellow members. A profile, for me, is basically sharing your identity with others.

I think as a pain patient, my identity has expanded from being, in the past, a Visual Artist and Learning Consultant to presently, being an advocate for better pain management in Ontario. This includes supporting Action Ontario in all their efforts to better educate government bodies and the general public regarding the requirements for a Comprehensive Pain Strategy in Ontario.

Along with managing my chronic pain, the most difficult challenge for me has been dealing with the isolation from family and old friends, who don't understand the impact of chronic and severe neuropathic pain. Dealing with persistent pain and its ramifi-



Julie Feldman

cations has truly been the biggest challenge I have ever faced in my life. I must thank my husband Brian and family for their ongoing support, and Dr. Angela Mailis-Gagnon and my peers at Action Ontario for their continuous enthusiasm and friendship.

My life now is completely focused on rehabilitation; that is mentally, physically, and emotionally. I take medication, attend Tai Chi class regularly, developed a slow cardio program, try to eat well to control inflammation, obtain counseling when required, and more importantly just try to relax and feel part of the world again.

Patient Voice First

(Continued from page 1)

the front lines of administering to the neuropathic and chronically ill patient on a day to day basis, but they see all too often the inadequacies in a system that does not support the family and the patient alike.

Catherine Dunlop, mother of Veronica Dunlop spoke of how her daughter's neuro-

pathic pain has changed every aspect of her family's life including the loss of her own job. She also echoed the sentiments of other panellists as to the social isolation and changes which occur in the family dynamics as a result of this. She insisted however, that despite the challenges Veronica's illness has brought to the family "she wouldn't trade her for anyone in the world."

"We are the backbone of the system when the system fails the chronically ill," said Phil Frampton, husband and caregiver of ACTION PNP Co-Chair Janice Frampton. "Yet no one acknowledges us when we fall down. If not for thousands of men, woman and adult children like myself who see no option but to stay home and take care of our loved ones, our provincial health-

care system would be overwrought with requests for assistance or worse still, there would be more deaths from neglect."

www.actionontario.ca

ACTION ONTARIO
For People with Neuropathic Pain
www.actionontario.ca



ACTION Ontario is an innovative not-for-profit organization whose mandate is to advocate on behalf of people 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 management. The board is comprised of university associated physicians, researchers and other health care professionals. As members of ACTION PNP each and every one of us is committed to improving the lives of People with Neuropathic Pain.

Optimism and Understanding Creates Hope

Application Form for ACTION Ontario PNP Committee Associate Membership

Please print and mail this form to the address provided below or email to: action-ontario@rogers.com
Membership application may also be made online at: www.actionontario.ca

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+

There are two types of membership on the PNP committee:

- 1) Regular members who are elected to serve on the PNP committee
- 2) Associate members who support the activities in meeting the goals and mandates of ACTION Ontario

Please check applicable designation: () *people diagnosed with Neuropathic Pain
() *people who wish to support the initiatives of ACTION Ontario/PNP
() *people who work with people with Neuropathic Pain and wish to support the initiatives of ACTION Ontario/PNP

Communications and newsletters are distributed by e-mail. Please provide a valid address for this purpose.

Email: _____

Referred By: _____

Date: _____

There is no fee for joining ACTION Ontario/PNP.

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

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