

Parkinson

PULSE

Connecting people living with Parkinson disease in Alberta



6th Annual

Hope Conference

Save the Date | May 23 & 24, 2014

Edmonton, AB

//Annual General Meeting
Friday, May 23, 2014

What I Learned P.4
at World Parkinson Congress

2014 Tulip Campaign P.12
The future's so bright

Tulip Campaign sales locations

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Pre-sales begin mid-February

Contact your Regional PA Office for more information or visit our website at parkinsonalberta.ca

Calgary

Suncor Energy Plaza – April 1 & 2 – 11am-1:30pm

Western Canada Place – April 8 – 9:30am-1:30pm

8th Ave Place – April 8 & 9 – 10am-2pm

Southcentre Mall – April 12 & 13 – 12pm-5pm

Edmonton

Downtown Farmer's Market – April 5, 12 & 19
9am-3pm

Kingsway Garden Mall – April 9 – 11am-5pm

Canada Place – April 15 & 16 – 9am-3pm

Grande Prairie

New Horizon Co-op – April 15-17

Save-on Foods – April 15-17

Lethbridge

Location(s) TBD

Medicine Hat

Medicine Hat Coop – April 22-25 – 10am-2pm

Wal-Mart SuperCentre – April 24 & 25 – 10am-2pm

Red Deer

Red Deer Hospital (by Café doors on Main floor)
April 10 & 11 – 10am-5pm

hope
grows

Parkinson
Alberta

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Winter 2014

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Parkinson Alberta

Who Are We?

Parkinson Alberta helps make every day better for Albertans affected by Parkinson disease (PD). We provide support services, education, advocacy and funds for research.

Parkinson Pulse is a quarterly publication of Parkinson Alberta. It is available free of charge to people living with Parkinson disease, their supporters, community health partners, and researchers.

We welcome your comments, suggestions and questions. Email us at communications@parkinsonalberta.ca; phone us toll free at **1-800-561-1911**; or mail to Parkinson Pulse at 102, 5636 Burbank Cres SE, Calgary AB, T2H 1Z6.

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103, 10901 – 100th St
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Medicine Hat Office

101, 928 Allowance Ave SE
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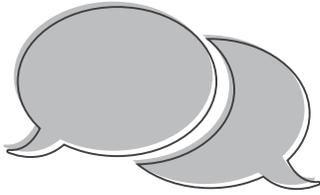
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Articles and information contained in the Parkinson Pulse are provided solely for the readers' interest. Articles do not necessarily reflect the views of Parkinson Alberta and are NOT intended as medical advice. Please consult your doctor or neurologist in all matters relating to health concerns or medication.



From the Desk of **THE CEO**

As we leave 2013 behind us, we look forward to a 2014 bursting with confidence, opportunity and hope.

Looking to the year ahead, we will continue to embrace the unique and dynamic nature of our work. To initiate when we can and adjust when necessary. The people we serve range in age, location, and need. We have long been believers in helping to personalize the support and services a person with Parkinson disease and/or their care-partner(s) and families require. We know that not all clients wish to nor need to receive the same level and array of services and support that Parkinson Alberta has available. We also know that too can change as a client's Parkinson's progresses. This is why we strive to cultivate and keep lines of communications open with the people we serve. Why we aim to develop supports and services that are adaptable to a range of client wants and needs. And why we are constantly evaluating our performance and making the necessary adjustments to be effective in the changing lives of those we serve.

Plans for 2014 include offering some of our information in additional languages, the expansion of programming into other areas, and creating new resources. We will also continue to be a valuable asset not only to those dealing with Parkinson disease, but to the medical community as well, by being a safe, educated, friendly and trusted resource for the Parkinson community.

Parkinson Alberta will continue to expand on and offer information and tools you can use to help you live better with Parkinson disease, regardless of where you live in the province. For example our newly designed website (read more on page 11) offers printable resources, our online "Ask the Experts", and in the future short videos to help educate and connect the Parkinson community. Additional tools include our toll-free PD Helpline, our social media interactions and an array of programming and educational opportunities across Alberta.

Information and tools will also be available on a larger-scale May 23 & 24, when our Hope Conference for Parkinson's returns. This year will be the 6th time we've held this incredible educational and networking opportunity. I

encourage you to consider attending this extraordinary event, more details are available on pages 14–16.

Like many businesses (especially non-profits), we live in a challenging economic climate, in a world that seems to change with every passing minute. Here at Parkinson Alberta we have a history of facing those challenges and finding opportunities in them; 2014 will be no exception. Our Fund Development Team has been actively refining and creating events and opportunities that will help us continue to fund new and existing services, programs and research. We have many initiatives planned for 2014 including favorites like the tulip campaign, golf tournaments and Step'n Stride. We've also got new projects and campaigns in the works like a new direct mail campaign which will arrive in some mailboxes in April and November. We are moving forward with a new planned giving platform to educate and inform individuals and families on ways to share hope via will and estate planning. And, we're also working on a plan that could potentially see Parkinson Alberta product (like clothing, memorabilia, etc) sold online, at events and from our offices.

Finally, April is Parkinson Awareness month – a time when the world pays special attention to Parkinson disease and those whose lives are touched by it. I urge you to help us ensure that we are seen and heard – to help us ensure that no one has to face this disease alone. Visit our website or give us a call to find out how you can get involved.

Our outlook can be summed up in one word: confidence. All the necessary elements for a successful 2014 are within reach and we are building a stronger foundation each and every day. The source of our advantage is simple; it is grounded in the engagement of people whose lives have been touched by Parkinson disease. Our success is in direct correlation to theirs – the people who we serve. Your victories, large and small, are our victories; and ours are yours. We look forward to working together with you to make 2014 the best and most successful year yet!

What I Learned at WORLD PARKINSON CONGRESS:

“Oh Lord! Please don’t let me be misunderstood!”

By Helen Mak

Have you ever struggled to lift your head up while walking, especially when you are off? Or have you been told numerous times “there is no money on the floor” but in fact all you can notice is how come your head suddenly feels like a ton heavy? If your response to these questions is a resounding yes, (because only God knows how hard you have tried) then you will definitely appreciate my elation about what I have learned at the World Parkinson Congress (WPC) in early October in Montreal.

After having Parkinson’s for more than a decade, this debilitating ailment has once again surprised me with its complexity and mystery. At this 3rd WPC, I stumbled upon a lecture of a lesser known topic called “Camptocormia”, which was presented by Dr. J. Jankovic, one of the renowned Parkinson specialists I admire deeply. It must have been fate that at this last talk on the last day of the Congress, one of three presenters was a no-show. As a result, Dr. Jankovic was able to take the time to explain the topic thoroughly and kindly answer all the questions from the floor. I was ecstatic after listening to the topic and felt an invisible veil had been lifted off my head. Finally after all these years, I now know what is happening to my right hand and foot!

Although my Parkinson conditions are still with me (I bet they are even progressing as I am typing on the computer), I felt connected and hopeful because I know there are people out there who care enough to want to understand how I feel. To that end, it is already good enough for me. For I believe, no matter how small



or slow our steps are, as long as we don’t give up, we can reach our goal. Maybe it will take a long time to get to the destination, so what? After all each of us has our very own battle to face, I just want to be understood.

To make the long story short, here is what I have learned about “Camptocormia”. If you do struggle with this symptom, remember, it is imperative for you to seek help from your medical care provider(s).

- » Also known as Bent Spine Syndrome, Camptocormia is defined as an abnormal (a minimum 45° anterior) flexion of the trunk that appears when standing or walking and disappears in the supine position. In other words, a patient is said to have this condition if the neck or trunk is bent forward at least 45° away from normal upward position, standing or sitting but not when lying flat.
- » This rare symptom usually found in seniors, is often attributed to normal aging and hence not diagnosed. The term “Camptocormia” is derived from two Greek words “kamptos”(to bend) and “kormos” (trunk). Camptocormia in Parkinsonism has long been thought as incidental or even psychogenic; therefore very little attention has been paid to attempt further understanding of this condition.
- » The onset of Camptocormia is found to be fairly rapid and progressive (a couple of weeks). Though rarely associated with pain, patients have reported that symptom worsen with time and fatigue during the day.
- » Etiology of the disorder is unknown, but it is usually attributed either to a primary or a secondary paravertebral muscle myopathy or a motor neuron disorder. Camptocormia has been found not only in Parkinson and/or dystonia, but more often in Progressive Supranuclear Palsy, Multiple System Atrophy, Tourette syndrome, Myasthenia Gravis and Amyotrophic Lateral Sclerosis. In one study of 202 people, it has been found in ~30% of PD, over 68.4% in Multiple System Atrophy, and 26% in PSP.
- » Abnormal flexion can also happen to peripheral joints, known as Striatal hand and foot. These deformities are common in patients with

advanced PD but can occur in early stages of PD and in other Parkinsonian disorders. Pathology in the neostriatum (putamen and caudate) has been suggested to cause the deformities, but the pathogenesis is still unknown. Often being misdiagnosed as rheumatoid arthritis in the past, more severe ones are actually related to extensor muscle myopathy. Medications like dopamine agonists (e.g. Pramipexole) have been implicated.



- » Should be treated as early as possible for best results, i.e. before myopathy sets in. Intervention can be using support devices such as a backpack, slightly heeled shoes, and crutches. Severe cases can pursue Lidocaine injection in abdomen, and/or STN DBS (for off-time dystonia). For mild cases, simply lying in bed for an hour in the afternoon might be all is needed, or cut back on DA agonists or with corticosteroid.

If you'd like to share your story, please contact Brandi at blabonte@parkinsonalberta.ca or 780-425-6400 ext 225

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- » Azher S, Jankovic J. Camptocormia: Pathogenesis, classification, and response to therapy. *Neurology* 2005;65:3:355-359
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Ask the EXPERTS + A

Question: Can my husband continue to drive? He is at the early stage of PD. Does he need to report his illness to his insurance and the Motor Vehicles bureau? Can we get an assessment test for his driving abilities at this time and over time?

Answer: As operating a motor vehicle is such an important part of life in Alberta, a frequently asked question from a person with PD (PWP), and family, is whether he/she is still safe driving. We will only address Class 5 driving licenses as Classes 1-4 have stricter requirements. It should be remembered that driving is a privilege, not a right.

In early stages of PD, there generally is no cause for concern. However, according to the Department of Motor Vehicles, this medical problem should be reported to them. With progression and the development of fluctuations, difficulties with driving may emerge. This should be addressed with your physician, who may ask such things as does the family have concerns, or has the PWP had any recent accidents. Testing of memory and cognitive function may be administered, such as the Montreal Cognitive Assessment (MoCA), or Mini Mental State Exam (MMSE). Finally if the answer is unclear an assessment by DriveABLE, or other similar agency, may be recommended.

In situations where the PWP has unpredictable fluctuations, and /or has developed cognitive problems or dementia, driving has to be given up. If the person in this situation does not want to give up driving, then he/she must be reported to the Department of Motor Vehicles and their license will be reviewed. This reporting can be done either by the physician, or concerned family members.

Parkinson Alberta has gathered an exemplary team of experts to answer your PD questions in a feature on our website aptly named "Ask the Experts". Our experts address questions on everything from symptoms and treatments, to medications and research, to alternative therapies.

If you have any questions, please contact:

Driver Fitness and Monitoring Branch
Main Floor, Twin Atria Building
4999 - 98 Avenue
Edmonton, Alberta, Canada T6B 2X3
Tel (780) 427-8230
Fax (780) 422-6612
e-mail: driver.fitness@gov.ab.ca

or visit the Alberta Transportation and/or Saferoads web sites at www.trans.gov.ab.ca or www.saferoads.com

Question: What kind of exercise is possible and beneficial for a 77-year-old female suffering from Parkinson disease, asthma and osteoporosis?

Answer: In the case of a person with Parkinson's who also has other comorbid conditions, the best answer is to have an individualized assessment with a physical therapist to determine which types of exercises may work best for this patient. Some classes or programs that take a one-size-fits-all approach may not be suitable for this particular patient. Please check with the physical therapist to see if they have specific knowledge and experience with their conditions.

A great article on this topic titled "Driving and Parkinson disease: What you Need to Know" ran in our Winter 2013 newsletter visit website at parkinsonalberta.ca/parkinson-alberta-newsletter to read it!

If you have a question you would like to ask, visit us online at www.parkinsonalberta.ca/ask-the-experts

Physical Activity: ROADBLOCKS & SOLUTIONS

Tara Chisholm

Masters of Arts Student in Adapted Physical Activity
University of Alberta

People with disabilities, particularly those who are inactive, have a greater risk of developing a variety of health conditions such as, cardiovascular disease, diabetes, and depression¹. For Parkinson's patients, there are many known benefits to becoming physically active. A recent study by The Ohio State University Wexner Medical Center² found that long-term group exercise programs improved depression. A review out of the United Kingdom reported that exercise is also beneficial for individuals with Parkinson disease as it improves quality of life, daily physical activity, strength, balance and walking speed³.

It's Not So Easy!

Although the benefits are clearly shown, it is not always easy for individuals with disabilities to become active. People with disabilities experience a range of barriers associated with physical activity participation. Some of the top barriers to physical activity for individuals with disabilities are⁴:

- » Cost
- » Transportation
- » Lack of information on programs
- » Inaccessible facilities
- » Poor Weather
- » Attitudes

What Can We Do?

The benefits of physical activity are too high not to do something. Researchers who have studied barriers and facilitators in large cities have a few suggestions of ways that individuals with disabilities can get active:

- » Check into subsidization of programming
- » Go with a family member or friend
- » Check with a local Parkinson Alberta Office about programs

- » Find programming close to home, if possible
- » Talk to fitness instructors about accommodations for your needs

It's Okay to Ask for Help

Obviously these solutions are easier said than done. Like anybody preparing to be physically active, it is up to the individual to decide if they are ready to commit to trying a program. This is where an organization such as Parkinson Alberta can play a large role to assist in finding options that work best for you.

What's Next?

As you have seen listed above, in large metropolitan cities there has been a great deal of research surrounding barriers and facilitators to physical activity programs for individuals with disabilities. The University of Alberta is now studying if there is a difference between large cities and small towns in what helps or does not help individuals with disabilities to become physically active. The results may provide direction for practitioners and policy makers who seek to make physical activity opportunities more accessible to all people in small Canadian communities and contribute to better health for people with disabilities.

References

- 1 Cooper, R.A., Quatrano, L.A., Axelson, P.W., Harlan, W., Stineman, M., & Franklin, B. (1999). Research on physical activity and health among people with disabilities: A consensus statement. *Journal of Rehabilitation Research and Development*, 36(2), 142–154.
- 2 Park, A., Zid, D., Russel, A., Malone, A., Rendon, A., & Wehr, X. (2013). Effects of a formal exercise program on Parkinson's disease: A pilot study using a delayed start design. *Parkinsonism & Related Disorders*.
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PD & Constipation

Constipation is a challenge facing many people. Having constipation while living with Parkinson disease (PD) can have a negative impact on your enjoyment of life. Arming yourself with information to prevent or manage constipation is an important part of living well and promoting a healthy lifestyle

What is constipation?

It is a myth that you must have a bowel movement/pass stool/"poop" at least once a day. Many things influence the frequency of bowel movements: age, diet, medications, stress, inactivity, and having PD or other medical conditions. A normal range is 3 times a day to 3 times a week. The stool you pass should be soft, easy to pass and, at the end of it, you should feel that your bowel is "empty". Infrequent bowel movements (fewer than every 3-4 days), a stool that is hard and dry, or straining to expel it, may mean constipation. It is time to act!

Being constipated can be more than just a nuisance. It may interfere with how well your medications are absorbed, making them less effective. Being constipated can make you feel unwell, uncomfortable, irritable, nauseated or lethargic. In severe cases, it can lead to a blockage of the intestine (impaction), making it impossible to pass any stool. In very rare circumstances, impaction requires urgent medical attention. Constipation may also disturb your bladder function and may make you feel that you need to urinate more frequently and urgently.

Parkinson disease and constipation

Not everyone who has PD has constipation. However, many people with PD deal with constipation and it can be a real burden. PD affects the bowels in a number of ways:

- » Just as the muscles in your arms, legs, trunk and face may be slower and stiff, the muscles of your intestines (bowels) may also have reduced mobility. With slowed mobility, the stool ("poop") does not move very quickly through the bowel. This may cause constipation. The muscles involved in emptying the bowels may also be affected by PD and may not be as coordinated as before. They may not be able to relax, making it more difficult to eliminate the stool completely.
- » Certain drugs used to treat PD symptoms may cause constipation or affect your appetite. If you start a medication and you notice a change in how frequently you have a bowel movement, contact your healthcare team. They will review all your medications and make recommendations.

Not drinking enough fluids and difficulty chewing and/or swallowing can contribute to constipation as well. Trouble with chewing and swallowing can make it hard to get enough fibre in your diet.

Additional information on this topic

PD & Constipation: Prevention and Management

is available on our website or through your Client Services Coordinator.

GOOD SLEEP HABITS

From Patrick McNamara, Ph.D., *About.com*

Parkinson disease often takes a toll on our sleep. The muscle cramps can wake you up several times a night. The stiffness and rigidity of PD makes it difficult to get comfortable. Going to the bathroom in the middle of the night can become a herculean task that consumes a lot of sleep time. A depressed mood can disrupt sleep cycles until you find yourself waking too early in the morning and not being able to get back to sleep. Some of us have restless legs syndrome where you feel you have to move your legs around a lot and that feeling will of course keep you awake. Many of us have intense dreams and sometimes nightmares and these bad dreams can wake us up. All too often we awake in the morning not feeling really rested so we go through the rest of the day feeling tired, irritable and sleepy.

So what do you do about all these sleep problems? Certainly speaking to your doctor is a good idea. There are medicines that can help you sleep. The active cultivation of good sleep habits is easy to dismiss but can be useful, although you must avoid an ineffectual piecemeal "Band-Aid" sort of approach to a really troubling set of medical problems. But these habits, once acquired, really do make a difference and they are worth the effort involved to acquire them.

Take the next two weeks and promise yourself that you will do your best to enact and acquire the following sleep habits:

- » **Stay on schedule:** Go to bed and get up at roughly the same time each day. Schedules help your body and your internal clock to initiate sleep and wakefulness.
- » **Exercise** at least 20 minutes each day — preferably in the morning. Daily moderate exercise improves sleep in myriad ways, such as stimulating the release of sleep-inducing hormones. But don't exercise right before going to bed because it arouses you.



- » **Create a comfortable sleeping place;** a cool, well ventilated room without noise, people (except your bed partner of course), TV, food or other distractions.
- » **Reserve your bed for sleep.** Don't use it regularly for other activities like reading, watching TV, or talking with others.
- » **Avoid large meals and too much drink when sleep time approaches.** A snack is OK.
- » **If you wake up during the night and can't easily fall back to sleep, try reading a book.** Listening to relaxing music or meditating but avoid TV, talking with others or telephone.
- » **Be patient** with yourself and your PD.

The experience of thousands of people has suggested that these simple sleep habits actually work pretty well. They certainly can't hurt you! Acquiring them, so that they become regular habits, will take a couple of weeks of faithful adherence but once you have them they will pay dividends back to you in better quality sleep for the rest of your life.

EVENTS

+ updates

UPCOMING EVENTS

February 2014 *(every Friday)*

Edmonton – 9:00-10:00 pm – Moksha Yoga (14927 – 111 Ave)
For a minimum \$5 donation you can get fit and have fun all for a good cause with Karma yoga classes hosted by Moksha Yoga. Due to the popularity of the Karma classes it is recommended that participants arrive 30 minutes early.

March 16-20, 2014

Calgary – We are honored to announce that PA has been chosen as one of the Charities of Choice for the 21st annual Oilympics Charity Hockey Tournament! For more information on the tournament please visit www.oilympics.com.

April *(all month long for Parkinson Awareness)*

Calgary – each month Wild Rose Brewery (4580 Quesnay Wood Dr SW) is helping raise funds via pint sales in the taproom. During the entire month of April, \$0.25 of every featured pint purchased will go towards PA!

Medicine Hat – Looking for something new and exciting to have for lunch/dinner? Visit Weenie Hot Dogs & Macaroni (547 – 4th St SE) and try PA's soon-to-be-famous "Tremor Dog"! \$1 from every Tremor Dog sold will go to PA!

April 26, 2014

Medicine Hat – 8:30-11:00 am – Hillcrest Church (3785-13th Ave SE) – \$5/person

Pancakes for Parkinson's will be a first for Parkinson Alberta! Bring the family, friends or neighbors for a wonderful breakfast of pancakes and sausages. Volunteers are always welcome, call PA Medicine Hat Office if you can help out.

May 9 & 10, 2014

Medicine Hat – 9:00-4:00 pm – Kinplex Kin Social Room (2055 – 21st Ave SE)

Parkinson Support Group Annual Charity Garage Sale is being held once again this coming spring. Donations of gently used items can be dropped off at the Kinplex on May 8 from 9:00AM-3:00PM (no furniture, baby seats or clothing please).

PAST EVENTS

Bottle Drive

The fine people of Medicine Hat and Redcliff took advantage of Shamrocks Bottle Depots Charity of Choice Program in August and September donating their recyclables to Parkinson Alberta. Thanks to everyone's efforts, \$1106.75 was raised for PA!



Hope for the Holidays – Poinsettia Campaign

This trial campaign was conducted in Calgary this past holiday season. November and December saw us host over a dozen locations and sell over 800 poinsettias, all in support of PA. The inaugural campaign raised over \$2,500!

MyLawTeam.ca Charity Golf Tourney

PA Grande Prairie was chosen as one of the charities of choice at the 2013 tourney. We had so much fun and people had a great time participating in our hosted challenge, in the end \$3,968 was raised for PA!

Welcome to Our New Website –

YOUR FIRST STOP FOR PARKINSON INFORMATION

Parkinson Alberta is excited to announce the official launch of our new website! The website, located at the same address – parkinsonalberta.ca – has been redesigned to improve user friendliness and appeal. Special thank you to Dean Heuman and incredible staff at Focus Communications for all their hardwork in making this possible.

The site's homepage welcomes visitors with our bright, bold colors, a clean design, and easy to navigate layout. It features content focused on Parkinson Alberta's dedication to help make every day better for people whose lives have been touched by Parkinson disease.

Besides basic information (news & updates, contacts, etc), the website is divided into four main sections: Get Answers, Get Support, Get Involved, and Research.

- » **Get Answers** is your go-to section for questions, answers and information on Parkinson disease; including printable resource materials and our online "Ask the Experts" tool.
- » **Get Support** is your access point for personal support containing information on support groups, regional programming and our province-wide toll-free PD Helpline.
- » **Get Involved** highlights the many ways you can engage with Parkinson Alberta – from memberships, events, and volunteering to making a donation. It's never been easier!

- » **Research** – though still in its developmental stages, it is our hope that in the near future this section will be your first stop for all things Parkinson research related.

This approach makes it easier for visitors to have direct access to the information they need based on their own choices rather than sifting through endless pages to find what best suits their needs. Additionally, the website features links to all of our social media platforms (including a live Twitter feed) and showcases our Faces of Parkinson's Campaign.

"The new website marks another target achieved in Parkinson Alberta's strategy to improve and expand access to Parkinson information and support", said John Petryshen, CEO. "It gives our current and potential clients another avenue to interact with Parkinson Alberta and access the information, support and services they need to live better with PD."

We're delighted to be launching a new website; but we also believe that a great website is never really finished! Our website will become the launching point for many exciting new features we will unveil in both the near and distant future. Some of our planned initiatives include, online registration for events, an online marketplace, a private area for our members to access special content and videos, and a collection of web based tools and resources we've dreamed up to help everyone live better with PD.

We hope you enjoy visiting and exploring the new parkinsonalberta.ca website. Please feel free to send any comments or feedback you may have to communications@parkinsonalberta.ca.





2014 Tulip Campaign:

“Where hope grows, miracles blossom.”

A wonderful quote by Elna Rae and a great lead into the kickoff of our annual tulip campaign. Building on the great successes of 2013, Parkinson Alberta (PA) is once again going to start spring off right with our annual tulip campaign – Hope Grows (formerly Hope in Bloom).

Our tulips make appearances in shopping centers and hospitals, in downtown office towers and grocery stores, in retirement communities and churches. Very often by selling a supporter a little piece of spring we are also introducing Parkinson Alberta to the public at large and letting them know about the incredible support services and programs we offer. Hope Grows also provides funding to support Parkinson Alberta’s commitment to provide vital programs and services across the province. Individuals new to PA are often very pleasantly surprised at the depth and breadth of programs and support services we have available. A complete list of programs and services is available on our website, www.parkinsonalberta.ca.

2013 was our first year taking this program province-wide and we are very pleased we did; as last year our tulip campaign raised almost \$20,000. This year we are planning on even greater successes. We have already placed larger orders and started to organize new locations across the province. Selling tulips may seem to be a long way away from providing Support Groups

all across the province, but the funds collected and the awareness provided is invaluable.

Our tulips will once again be sold for \$8/pot. The pots are brightly wrapped, and best of all the bulbs can be replanted in the fall for a beautiful reminder in the spring. Muttart Conservatory in Edmonton will once again supply the tulips for Red Deer, Edmonton, and Grande Prairie; while Burnaby Lake Greenhouses will supply Medicine Hat, Lethbridge and Calgary. Hope Grows will begin the pre-sale portion of the campaign in mid-February, with physical sales locations beginning in April, just in time for Easter and of course, Parkinson Awareness Month!

Please contact your local Parkinson Alberta office to place your orders and look for our amazing team of staff and volunteers in your community and get a head start on spring!

If you would like to be a part of this bright and cheerful event, volunteers are always welcome! To help us make Hope Grow please contact your local Parkinson Alberta Office today.



NEWS + updates

Education Days

Red Deer

April 16, 2014 – All day

\$10 registration fee (includes lunch)

Speakers confirmed to date are a psychologist speaking on caregiver challenges and a recreation therapist speaking on fun and fitness.

There will be more speakers, as well as education displays

Medicine Hat

April 22, 2014 – 10AM-2:30PM – Terrace Rm, 2801-13 Ave SE

\$20 registration fee (includes lunch)

NEW this year: WeCare Home Health Services will be providing companionship care in the afternoon for those persons in need.

Pre-registration is required by April 15, 2014 contact PA Medicine Hat Office (403-526-5521)

Instagram

Looking for more ways to keep in touch with Parkinson Alberta?

Follow us on Instagram
[@parkinsonalberta](https://www.instagram.com/parkinsonalberta)



UPDATES

- » Are you or do you know someone under the age of 45 who has PD? PA Edmonton Office is creating a new program to suit the needs of younger persons with Parkinson's. Join us February 26, 2014 at 6:30PM to share your ideas and interests. Call 780-425-6400 for more information.
- » Be a part of the Brighter Day Program in Calgary, volunteer families and/or individuals with PD are needed to work with 3rd-yr nursing students from Mount Royal University from March – April 2014. Contact PA Calgary Office (403-243-9901) for more information.
- » "The BUFF's" Lending Resource Library - Thanks to the Association of the Medicine Man Lodge #10341 and Thunderbird Lodge #19 Royal Antediluvian Order of Buffaloes "BUFFS", the PA Medicine Hat Office has a lending library stacked with new fiction, non-fiction, & educational books and material, DVD movies and 2 Kindle E-readers for members to borrow out from. Feel free to drop in and see what the shelves are carrying or contact PA Medicine Hat Office (403-526-5521)
- » New Support Group – In light of overwhelming numbers, a second Sherwood Park support group is being piloted. This support group will run the first Thursday of the month from 6:30pm – 8:30pm, please contact PA Edmonton Office (780-425-6400) for more details.

6th Annual

Hope Conference

Join us for this incredible education and networking opportunity!

Choosing Hope

On May 23 & 24, Parkinson Alberta's 6th annual Hope Conference for Parkinson's will return to Edmonton. The conference is Alberta's largest Parkinson gathering, and is a great opportunity for the Parkinson disease (PD) community to get together to find out about the latest in research, learn practical tips and tools for living better with PD and discuss topics, experiences and ideas with peers. This conference is for people with PD, their care-partners and families, healthcare professionals and students in the healthcare fields

Choosing Hope, the theme of this year's conference, will offer two excellent speakers, six breakout session topics to choose from and the addition of a Friday plenary speaker. The conference aims not only to educate those whose lives have been touched by PD, but to expand social networks creating a larger, more active PD community.

The conference begins with a robust half-day on Friday that includes PA's Annual General Meeting, a plenary speaker presentation, dinner, program and our Keynote Speaker. Saturday includes featured

motivational speaker Ben Petrick, two breakout sessions, demonstrations, lunch, and the always popular Expert Panel Q&A session.

The Delta Edmonton South Hotel & Conference Centre will once again host the Hope Conference and is offering a special room rate of \$159/night (plus taxes) to all conference attendees. To receive your special rate please call 780-434-6415 or toll-free 1-800-661-1122 no later than Friday, April 25, 2014 and be sure to let them know you are with Parkinson Alberta's Hope Conference.

Registration for the conference can be done via a traditional paper form (see page 16) or online through our website. New to the online registration offering this year is a 3-month payment plan, which will give attendees the opportunity to pay their conference fees in smaller increments. It should also be noted that breakout sessions will be filled as registrations are received, so be sure to sign up early to ensure access to the topics you desire. Speak with your regional Client Services Coordinator or visit us online (parkinsonalberta.ca) to find out more.

BREAKOUT SESSION TOPICS

1. Sexuality & PD

This session will explore sexuality and disability with a focus on a couple's relationship and communication.
Presenter: Dr. Shaniff Esmail

2. Keeping Hope Alive

Managing the difficulties of living with a chronic illness while keeping our outlook hopeful.
Presenter: TBD

3. Deep Brain Stimulation

Learn about Deep Brain Stimulation from a Surgical Nurse Clinician, in this informative session.
Presenter: Karen Hunka

4. Moving On

Physiotherapists will share their expertise and demonstrate ways to keep you moving with confidence.
Presenters: Cari-Anne Cooke & Susan Loewen

5. Care-partner Care & Concerns

Learn valuable tools to use in your everyday life to help manage the stresses that can occur as a family care-partner.
Presenter: TBD

6. Voice & Speech Therapy for PD

Join us for an interactive session that will teach techniques to keep your voice alive.
Presenter: Dr. Merrill Tanner

2014

HOPE CONFERENCE ITINERARY

Friday, May 23

12:00 – 2:00 pm – Annual General Meeting Registration

12:00 – 3:00 pm – Hope Conference Registration

2:00 – 3:30 pm – Annual General Meeting

3:30 – 4:30 pm – NEW Event – Plenary Speaker TBD

4:30 – 5:00 pm – Break/Hotel Check-In Opportunity

5:00 – 5:15 pm – Doors to Banquet Room open/cocktails

5:15 – 6:45 pm – Dinner

6:45 – 7:15 pm – Program & Awards presentation

7:15 – 8:15 pm – Keynote Speaker: TBD

8:15 – 9:00 pm – Social

Saturday, May 24

8:00 – 9:30 am – Hope Conference Registration

8:30 – 9:00 am – Coffee & muffins

9:00 – 10:00 am – Featured Speaker: Ben Petrick

10:00 – 10:15 am – Break

10:15 – 11:15 am – Breakout Session #1

11:15 – 11:30 am – Break/Hotel Check-Out Opportunity

11:30 – 11:45 am – Choir Showcase

11:45 – 12:45 pm – Lunch

12:45 – 1:00 pm – Demonstration

1:00 – 1:15 pm – Break

1:15 – 2:15 pm – Breakout Session #2

2:15 – 2:30 pm – Break

2:30 – 3:30 pm – Expert Panel Q&A

3:30 – 3:45 pm – Closing Remarks

Registration form on reverse

Featured Speaker: Ben Petrick



Ben Petrick made his Major League Baseball (MLB) debut in September 1999 for the Colorado Rockies, what the world and even Ben himself didn't know was at the same time he was beginning to experience his first symptoms of

Parkinson disease. Ben would continue to play in the MLB for both the Colorado Rockies and the Detroit Tigers until his retirement in May 2004. It was only then that Ben announced publicly that he had been diagnosed with Parkinson disease – the same disease with which his father, Vern, had been living with since 1999. In 2009, Ben underwent Deep Brain Stimulation; and again a year later, this time emerging with incredible results.

Today, Ben is an active husband, father, author, baseball coach and advocate for Parkinson disease.

What People said in 2012

"I came with my Mom, who has Parkinson's, we both learned so much" - Debra

"It was great to spend a couple days with people who understood what I was feeling and going through. I felt like I was a part of something special!" - Harold

"This was my first conference. What an amazing experience! Everything was thought of – sessions, speakers, breaks and meals – with Parkinson's in mind. I never felt rushed or overwhelmed. It was great!" - Angela

6TH ANNUAL HOPE CONFERENCE FOR PARKINSON'S

Be sure to register early as sessions fill up quickly

REGISTRATION FORM

REGISTRATION INFORMATION

Name (First and Last)

Address

City

Province

Postal Code

Phone Number

Email Address

DELEGATE INFORMATION

Delegate 1

Person with PD

Newly Diagnosed

Young Onset

Caregiver

Healthcare Professional

Other

Delegate 2

Person with PD

Newly Diagnosed

Young Onset

Caregiver

Healthcare Professional

Other

CHOOSE YOUR SESSIONS

Please indicate the numbers of your top two Session choices plus an alternate. Though every effort will be made to ensure your top choices, Breakout Sessions are filled on a first come, first serve basis.

Please indicate THREE Session choices (by Session number - 1 thru 6):

Delegate 1 Name

Session Number

Session Number

Alternate Number

Delegate 2 Name

Session Number

Session Number

Alternate Number

CONFERENCE PRICING

Full Registration

Single (Member) – \$145 (before April 30) \$155 (after April 30)

Single (Non-member) – \$175 (before April 30) \$185 (after April 30)

Couple (Member) – \$249 (before April 30) \$259 (after April 30)

Couple (Non-member) – \$279 (before April 30) \$289 (after April 30)

Friday, May 23 Only (Including Dinner)

Single (Member) – \$75 (before April 30) \$85 (after April 30)

Single (Non-member) – \$105 (before April 30) \$115 (after April 30)

Saturday, May 24 Only (Including Lunch)

Single (Member) – \$95 (before April 30) \$105 (after April 30)

Single (Non-member) – \$125 (before April 30) \$135 (after April 30)

PAYMENT METHODS (or Register and Pay Online Starting February 14, 2014 at www.parkinsonalberta.ca)

By Cheque (Mail-in or drop off only; payable to Parkinson Alberta)

By Mastercard

By Visa

By Amex

Name as appears on the card

Card Number

Expiry Date

MAIL OR FAX YOUR REGISTRATION FORM:

Parkinson Alberta Calgary Office
102, 5636 Burbank Cres SE
Calgary, AB T2H 1Z6

Parkinson
Alberta



SUPPORT GROUPS

Please note that support groups run from September through June unless otherwise indicated.

CALGARY REGION		Tanya Good/Kate Tuff 403-243-9901
AIRDRIE		
3rd Monday of the month	10:00 am – 11:30 am	Cam Clark Ford – 1001 Highland Park Blvd
CALGARY		
1st Monday of the month	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
1st Thursday of the month	10:00 am – 11:30 am	Hope Lutheran Church – 3527 Boulton Rd NW
2nd Monday of the month	10:00 am – 11:30 am	McDougall United Church – 8516 Athabasca St SE
4th Monday of the month	10:00 am – 11:30 am	McDougall United Church – 8516 Athabasca St SE
4th Monday of the month Young Onset	7:00 pm – 8:30 pm	Hope Lutheran Church – 3527 Boulton Rd NW
COCHRANE		
2nd Thursday of the month	10:00 am – 11:30 am	St. Andrew's United Church – 128 – 1st St E
NANTON		
4th Thursday of the month	10:00 am – 11:30 am	St. Cecilia's Catholic Church – 2308 – 19th St
EDMONTON REGION		Susana Vela 780-425-6400
EDMONTON		
1st Wednesday of the month	1:00 pm – 3:00 pm	Rutherford Heights – 949 Rutherford Rd
3rd Wednesday of the month Young Onset	7:00 pm – 9:00 pm	PA Edmonton Office – #102, 11748 Kingsway
3rd Thursday of the month	7:00 pm – 9:00 pm	St. Joseph's Hospital – 10701 – 29th Ave
SHERWOOD PARK		
2nd Tuesday of the month	1:00 pm – 3:00 pm	Bethel Lutheran Church – 298 Bethel Dr
SPRUCE GROVE		
4th Thursday of the month	6:30 pm – 8:30 pm	Family and Community Services – #105, 505 Queen St
ST. ALBERT		
3rd Tuesday of the month	1:00 pm – 3:00 pm	St. Albert Seniors Centre – 7 Tache St
WESTLOCK		
Last Monday of the month	1:30 pm – 3:30 pm	Room 140, Provincial Bldg – #2, 10003 – 100th St
GRANDE PRAIRIE REGION		Genevieve Vaillancourt 780-882-3262
GRANDE PRAIRIE		
2nd Tuesday of the month	2:00 pm – 4:00 pm	Wildrose Manor – 9358 – 70th Ave
3rd Monday of the month Caregiver	12:30 pm – 2:30 pm	PA Grande Prairie Office – 103, 10901 – 100th St

! **INSIDER'S TIP:** Cut this page out to use as a quick & easy guide to support groups.



SUPPORT GROUPS

Please note that support groups run from September through June unless otherwise indicated.

LETHBRIDGE REGION		Brian Treadwell 403-317-7710
LETHBRIDGE		
3rd Thursday of the month	2:00 pm – 3:30 pm	Lethbridge Senior Citizens Org. – 500 – 11th St S
RAYMOND		
3rd Wednesday of the month	2:00 pm – 3:30 pm	Prairie Ridge Centre – 328 Broadway S
LLOYDMINSTER REGION		Barb Foxall 780-425-6400
COLD LAKE		
3rd Thursday of the month	7:00 pm – 9:00 pm	Cold Lake Regional Health Centre – 314 – 25th St
LLOYDMINSTER		
3rd Tuesday of the month	7:00 pm – 9:00 pm	Lakeland College
WAINWRIGHT		
3rd Tuesday of the month	2:00 pm – 4:00 pm	Provincial Building – 810 – 14th Ave
MEDICINE HAT REGION		Beth Metcalf 403-526-5521
BROOKS		
1st Wednesday of the month	1:00 pm – 3:00 pm	Orchard Manor – 951 Cassils Rd W
MEDICINE HAT		
2nd Tuesday of the month Carepartners	1:00 pm – 3:00 pm	PA Medicine Hat Office – #101, 928 Allowance Ave SE
2nd Wednesday of the month Men with PD	1:30 pm – 3:00 pm	Moose Lodge – #100, 2800 – 13 Ave SE
4th Tuesday of the month	1:30 pm – 3:00 pm	Kinplex Social Room – 2055 – 21st Ave SE
RED DEER REGION		Marilynne Herron 403-346-4463
LACOMBE		
4th Wednesday of the month	1:30 pm – 3:30 pm	Trinity Lutheran Church – 5227 C&E Trail
OLDS		
2nd Wednesday of the month	1:30 pm – 3:30 pm	Sunrise Village – 5600 Sunrise Cres
RED DEER		
3rd Wednesday of the month	1:30 pm – 3:30 pm	Davenport Church of Christ – 68 Donlevy St
THREE HILLS		
February 4th	2:00 pm – 4:00 pm	Community Drop In Centre – 160 – 3rd Ave S

Parkinson Alberta would like to thank the following sponsors for their commitment to ensuring that Albertans affected by Parkinson disease receive the quality and level of support and service necessary to live better with PD.



LAST LOOK:

PA's Annual General Meeting

Parkinson Alberta's (PA) Annual General Meeting (AGM) will take place on Friday, May 23, 2014 at 2:00PM. It will be held in conjunction with the 6th annual Hope Conference for Parkinson's taking place at the Delta Edmonton South Hotel & Conference Center in Edmonton. The AGM is open to all current Members of Parkinson Alberta, please note that Memberships will be available for purchase at registration (1:00pm-2:00pm).

To help us ensure that adequate printed materials are available, please let us know you wish to attend by registering. Registration can be done via email (info@parkinsonalberta) or phone call (403-243-9901 or 1-800-561-1911 toll-free).

Furthermore, the Nominating Committee is calling for nominations of candidates for the PA Board of Directors. All Directors will be elected for a two (2) year term (May 23, 2014 AGM – AGM 2016).

Our Mission:

Parkinson Alberta is the voice of Albertans and their families living with Parkinson disease. Our purpose is to ease the burden through advocacy, education, client services and find a cure through research.

What We Need:

Parkinson Alberta is looking for volunteers who represent geographic perspectives in Alberta and who will demonstrate excellence in their field of expertise and will bring to the Society a mix of leadership skills, care and vision critical to due diligence and good governance. Emphasis will be on recruitment of candidates who have the time, interest in a health charity and experience to make a significant impact on the long-term performance of Parkinson Alberta.

The Parkinson Alberta Board Governance Committee has reviewed the current PA Board composition and has determined the following additional skills and attributes will be required to carry out its mandate:

- » Marketing / Fund Development
- » Health Care Practitioner
- » Advocacy
- » Financial Expertise
- » Legal / Regulatory
- » Board Diversity (i.e. age, ethnicity, etc.)

Time Commitment & Involvement:

- » 4-6 in-person or teleconference meetings; and
- » Participation on one (1) Board Committee

If you have any questions about the criteria or process, please call 403-243-9901 or toll-free 1-800-561-1911. To be considered as a candidate, please complete the Nomination and Consent Form on page # and forward by 12:00PM (noon) on Tuesday, April 1, 2014 by mail, fax or email.

*Parkinson Alberta
#102, 5636 Burbank Cres SE
Calgary, AB T2H 1Z6
Attention: Chair, Nominating Committee
Fax: 403-243-8283
Email: miandolo@parkinsonalberta.ca*

Hav'n't gotten / renewed your

2014 membership?

Sign up online or call 1-800-561-1911.



Nomination and Consent Form

(Election to PA Board of Directors)

Section 1: Nomination

I, the undersigned, nominate _____ as a candidate for election to Parkinson Alberta Board of Directors for a two-year term for the years 2014-2016.

Address of Candidate: _____

Phone: _____ Fax: _____

Email: _____

A brief resume must accompany this form

Section 2: Nominator Information

Name of Nominator: _____

Phone: _____ Email: _____

Date: _____ Signature: _____

Section 3: Consent of Candidate

I, _____ consent to my nomination as a candidate for election to Parkinson Alberta Board of Directors for the year 2014-2016 representing a two-year term of office. I agree to stand for election and serve as Director if elected.

Date: _____ Signature: _____

Please send the completed Nomination and Consent Form by 12:00PM (noon) on Tuesday, April 1, 2014 by mail, email or fax to:

Parkinson Alberta
#102, 5636 Burbank Cres SE
Calgary, AB T2H 1Z6
Attention: Chair, Nominating Committee
Fax: 403-243-8283
Email: miandolo@parkinsonalberta.ca

6th Annual

Hope Conference

Early bird registration fee available until

April 30, 2014

See page 16 for more information on early bird pricing

Parkinson

Alberta

Would you like to see your company ad in the **Parkinson Pulse**?

Advertising rates and opportunities are available.



Contact:
Brandi LaBonte
communications@parkinsonalberta.ca
780-425-6400 ext 225



Don't live alone with Parkinson Disease.
We can help.
All you have to do is start the conversation.

Connect with the help you need

PD HELPLINE

Call 1-877-243-9992

Monday to Friday
8:30 am till 4:30 pm
Free from anywhere in Alberta



In affiliation with the Calgary and Edmonton Movement Disorders Programs

Parkinson
Alberta



April is **Parkinson** Awareness Month

Help us make every day better for those
affected by Parkinson disease

To find out how you can help, visit parkinsonalberta.ca or call 1-800-561-1911.

