

the
Parkinson

press

Summer 2018



It's a Bird! It's a Plane!

It's Ardyce Glessing!

The Power of Music

It's Stronger Than You Think!

Where to Turn

When your Loved One has Parkinson's



Connecting the Pieces

Could this Researcher Solve the Parkinson's Puzzle?





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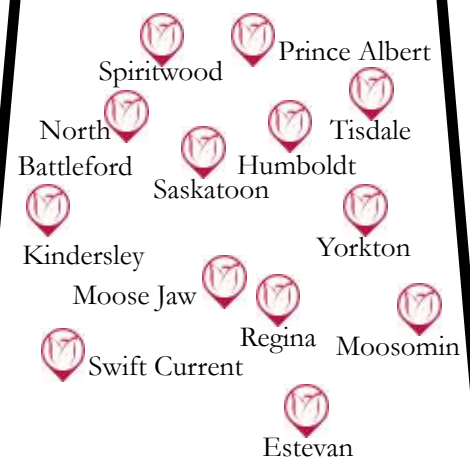
What We Do

Parkinson Canada is the national voice of Canadians living with Parkinson's disease. From diagnosis to discovery, we guide the way for Canadians to live well with Parkinson's disease through research, education, advocacy, and support. Whether you are an individual living with Parkinson's, a health care professional who treats them, or a family caregiver, we offer programs and services in communities coast to coast, in person, by telephone and online. The Parkinson Canada Research Program funds innovative research to search for better treatments and a cure. By working with all levels of governments, our advocacy initiatives focus on those issues of the greatest importance to the Parkinson's

Editorial Statement

The views and opinions expressed within the pages of *the Parkinson Press* are not necessarily those of Parkinson Canada. Articles contained in herein are for information only. Parkinson Canada does not guarantee nor endorse any product or claim. You should consult your physician and other healthcare providers before beginning any medical treatment, therapy, exercise, diet, or supplementation.

Find a Parkinson Canada Support Group near you!



THANK YOU SASKATCHEWAN!



Todd MacPherson, Managing Director

Last week, I enjoyed a prairie thunderstorm. Not the kind where you're worried about damage, but the kind where nature puts on a spectacular show. Lightning, thunder, and generous rainfall. I've loved a good thunderstorm ever since I was young. There is so much to enjoy about a Saskatchewan summer: thunderstorms, the big blue sky, the wind dancing over the fields, I could go on.

“We are surrounded by remarkable stories of everyday ‘heroes’ living with Parkinson’s.”

But the best thing about Saskatchewan is the people.

We are surrounded by remarkable stories of everyday ‘heroes’ living with Parkinson’s. And it is our privilege to share some of these stories with you in this newsletter, as well as on our Facebook page. Stories like Ardyce Glessing of Wadena, SK who is our national SuperWalk hero; and Janice Boucher of Prince Albert, SK who won gold at the World Para Reining International Championships.

When we ask people if we can share their stories, the #1 response is, “If you think it can help.”

That sentiment resonates throughout our province. I see it in the support groups that regularly gather to encourage and educate, and in the individuals who will happily take a phone call from someone newly diagnosed to answer their questions and convey that they are not alone. And I see it in the committees and support groups preparing for SuperWalk this fall.

In this issue of the Parkinson Press, you will find information on a SuperWalk near you. Whether the SuperWalk is a large community event or a smaller support group activity, the message is the same, “Everyday heroes, extraordinary hope!” I trust we’ll see you at a walk this fall.

On behalf of the Parkinson Canada team, let me say thank you for the generous donation of your time, money and energy. Thank you for the simple ways you help to touch the lives of others living with Parkinson’s.

- Todd

**There is Help and Hope at
Parkinson Canada**



What *Moves* You?

Our Education conference was alive this year with all the movement presentations. And indeed, something special happened on Friday night and again on Saturday afternoon when Fran Gilboy had everyone experiencing the pure joy of dance. For someone with Parkinson's, feeling such a good connection with movement can be especially thrilling.

The soundtrack to Fran's dance classes plays an important role in creating an uplifting, meaningful, and fun atmosphere!

On our path to better physical and mental health, perhaps we should all pay more attention to the use of music in our lives; certainly, for those with Parkinson's disease, this can contribute significantly to "Living Well with Parkinson's."

In fact, there's been a lot of interest and research in regards to music and Parkinson's. Neuroscientists are exploring the specific changes that happen in different parts of the brain when music, and especially *music with movement*, are used to help relieve some of the symptoms of Parkinson's. Some of the most common areas examined are: ease of movement, initiation of movement and improved sense of 'timing' (which can help with the slow speed), bradykinesia, as well as freezing.¹ Some researchers have identified

lower levels of anxiety and cortisol², both areas of concern in the management of Parkinson's. Daniel Levitin, a prominent neuroscientist at McGill, is leading current research in the field. He has even seen evidence of music being associated "with immunoglobulin A, an antibody linked to immunity, as well as higher counts of cells that fight germs and bacteria."²

Additionally, brain scans have shown increased activity upon listening to music in areas related not just to movement, but also to attention, planning, and memory². Of course, these cognitive changes often pose real challenges with Parkinson's. How wonderful if there is a therapy right in front of us which can potentially assist in so many of these areas!

¹ Sacks, Oliver. "Chapter 20: Kinetic Melody: Parkinson's Disease and Music Therapy." *Musicophilia: Tales of Music and the Brain*. Picador, 2012.

² Landau, Elizabeth. "This is Your Brain on Music." CNN, 23 Jan. 2018.
Based on the book of the same title by Daniel Levitin.

Trying it Out

It has been noticed that many people with Parkinson's find that walking with music assists with gait, balance, and stride.

The next time you go for a walk, try using music in the background or with earbuds and notice any changes in your steps, timing, and balance.

Similarly, notice if there is any change in your thoughts and feelings; of course, since music and exercise both improve mood with the release of endorphins, it will be hard to identify which is causing this!



Some Ideas for Further Reading



Daniel Levitin: *This is Your Brain on Music*

Available through public libraries as hardcopy and as a CD

Dr. Levitin of McGill, described as “rocker-turned-neuroscientist,” has written for the general public about the connection between music and the brain.

“*The Musical Brain*” is a DVD that can be found at your public library which also features an interview with Dr. Levitin.



Oliver Sacks: *Musicophilia*

Available through public libraries as hardcopy and as a CD

Oliver Sacks, the well-loved Neurologist and writer, explores the mysteries of music in healing and how it influences the depths of the brain. Chapter 20 is even specifically geared towards music therapy for Parkinson's Disease.



Elizabeth Landau: *This is Your Brain on Music*

Article available on CNN.com

Based on the book by Dr. Levitin of the same name; Ms. Landau describes some of the brain chemicals, and some of the areas of the brain involved with music therapy, in a shorter, more digestible fashion.



Google Search: *Music and Parkinson's*

Of course, a Google search for the term “*Music and Parkinson's*” offers many more resources which may stimulate your interest in this topic. As with all information on the internet, be sure to use your judgement in the credibility of sources.

If you do not have access to or do not feel comfortable using a computer but are interested in these resources, please let our office know, and we can provide you with physical copies!

Care Givers, Care Partners: Let's Build Up Our Network!

Sometimes, it may seem as if information, advice, and support for care partners are located both everywhere and yet nowhere to be found when needed! We know that the need is great, and over the coming year, we at Parkinson Canada would like to focus on working with our members to ensure that care partners/caregivers are able to access the information and support which are so essential to our families.

It should be noted that for the purpose of this article, the term 'caregivers' is used to denote both caregivers and care partners.

Support Groups

Our Parkinson's Support Groups are meant to offer a safe and welcoming place for people living with Parkinson's—and that includes care partners! Care partners often go on to form an informal support network; they may chat after meetings, or call or visit to discuss their issues separate from the group. It is often easier to address concerns with others who share the same everyday experiences, especially when sharing frustrations in the presence of loved ones can sometimes result in a range of hurt feelings.



A wholly separate care partner's support group is a great idea, however not always possible due to other time commitments. An alternative, which has been done previously by some groups, is to reserve several meetings a year where the group divides into two groups: people diagnosed with Parkinson's, and care partners. This style can offer an opportunity to discuss the unique challenges that each group faces, in an environment surrounded by others experiencing similar problems.

In the future, Parkinson Canada is looking at the possibility of an Online Caregiver Group. This style of group has the potential to address the gaps in services for care partners, who are often already stretched to the limit and are unable to attend a meeting in person. A few different modes of delivery have been discussed, such as a regularly scheduled video or teleconference meeting, or even an online chat room which would foster continuous engagement. If this would be of interest to you, or if you have any further ideas, please contact Jennifer or Kelly to discuss further!

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Parkinson Canada Office

Our community development coordinators, Kelly Pierson and Jennifer Schoeck, are available and always happy to take your calls. They are here to offer support and information to all people affected by Parkinson's disease throughout the province.

Parkinson Canada is continuing to develop resources which can be obtained from our office as well as the website. There are several articles specifically for care partners. One tool, called *Taking Care of Yourself through the Ups and Downs of Caregiving* is based on a November 2017 webinar called *Coping with Parkinson's Disease*. Both resources can be accessed through the Parkinson Canada website (parkinson.ca), and clicking on the "Resources" tab.

A new *Manual for Care Partners* has also been written and is currently in final review. This resource will hopefully be published and available to the public soon.

Online Resources

Those who use the internet know that there is a wealth of information available at your fingertips. There are a number of helpful webinars and articles available, which can be enriching and validating for a care partner. It can be tough to know where to start looking for resources, so here are some recommendations:

The Caregiver Network

www.thecaregivernetwork.ca

TCN has joined with Huddol to create an interactive site which has a discussion forum as well as resources. There are many excellent videos which can be viewed under the "Events" tab.

Family Caregivers of BC

www.familycaregiversbc.ca

While many of the services offered by this group are BC-specific, most of the webinars and some of the articles are excellent and relevant for all.

Saskatoon Council for Aging (SCOA)

www.saskatooncaregiver.ca

The SCOA has a network of resources for caregivers, including a manual of resources and general information. While some of it is Saskatoon-specific, the management and self-care information is relevant to everyone.

The Family Caregiver Centre

family.caregiverscentre@albertahealthservices.ca (e-mail)

Based in Calgary, this is a valued service of Alberta Health. They have a journal titled "Journeys," published twice annually, which has good, practical articles. It can be e-mailed to you upon request.



WHO IS YOUR Hero?

Like many everyday heroes, Ardyce brings a 'no matter what' attitude to living well with Parkinson's:

"Some days, doing the best we can will fall short of what we would like to do. We must not dwell on what we can't do and be thankful for what we can. You may see me struggle, but you will never see me quit; we must keep going! To me, that is the key to living well with Parkinson's.

Who is Ardyce Glessing? Grandmother, caregiver, Saskatchewan resident, and this year's Parkinson SuperWalk National hero. Ardyce has been living with Parkinson's for ten years but has not let her diagnosis change her relationship with her family. The Wadena resident is active in the lives of her grandchildren and provides support for her 97-year-old mother as well. She reflects, "When someone has Parkinson's the whole family, and everyone who loves them does too. I did not really know anything about it until being diagnosed July 7th, 2008, a day that will always be etched in my mind."

Emotional support is one of the most important things that my friends and family can give me. They give me strength by being there for me, and by showing their support through Parkinson SuperWalk."

“ You may see me struggle, but you will never see me quit; we must keep going! ”



Need more pledge forms? Looking for information on local walks? Check out our website!

www.superwalk.ca



Register online at **superwalk.ca**

or call **1(800)565-3000**

PARKINSON CANADA SUPERWALK™ PLEDGE FORM

Participant information

First name		Last name		Email address	
Street address			City	Province	Postal code
Team name	Gender	Phone number	Including this year, how many years have you participated in SuperWalk?		

Team Captain?
☐ Yes ☐ No

Please select your age group
☐ Under 12 ☐ 12-17 ☐ 18-25 ☐ 26-40 ☐ 41-55 ☐ 56-64 ☐ 65+

Are you living with Parkinson's?
☐ Yes ☐ No

Waiver

I agree that I am participating in Parkinson SuperWalk (PSW) voluntarily and do so at my own risk. I hereby fully release Parkinson Canada, the corporate sponsors of PSW, and any other parties connected in any way with PSW, as well as their respective officers, directors, agents, employees, staff and volunteers, from all claims or lawsuits for any injuries, death, property damage or theft, losses, or any other liability of any kind, arising directly or indirectly out of my participation in PSW or any of the activities associated therewith. I consent to being provided with emergency treatment in the event of my illness or injury during my participation in PSW, and agree to not hold Parkinson Canada responsible for any costs associated with such treatment. I consent to the publication and/or other use of my name, voice, photograph or other likeness without further notice or compensation in any publicity or advertisement carried out by Parkinson Canada in any manner whatsoever, including print, broadcast, or the Internet. By signing below, I confirm that I have carefully read this Release and Consent and fully understand and agree to its contents.

Signature of participant

Signature of guardian (if under 18)

Privacy statement

Parkinson SuperWalk and Parkinson Canada collects personal information to communicate with supporters about initiatives and fundraising. By providing your information, you give consent to be contacted.

For a copy of our privacy policy visit parkinson.ca/privacy-policy, or please contact us: donating@parkinson.ca or call 1 (800) 565-3000.

Our sponsors



Every day
HEROES
Extraordinary
HOPE

 Parkinson Canada
Charitable organization number
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Cut along the dotted line

PARKINSON CANADA SUPERWALK™ PLEDGE FORM

Return or mail **your** pledge forms to a Parkinson Canada office by **August 31st** to make **your** check-in easier, and to see your updated total on walk day.

Mail to: Parkinson Canada
Attn: Parkinson SuperWalk
316-4211 Yonge Street
Toronto, ON, M2P 2A9

Please print clearly, complete all fields and do not include funds collected online.

Participant	Walk location	Team name
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Pledges

First name	Last name	Email address	Phone number
Address / City / Province / Postal code		Amount	☐ Cash ☐ Cheque

First name	Last name	Email address	Phone number
Address / City / Province / Postal code		Amount	☐ Cash ☐ Cheque

First name	Last name	Email address	Phone number
Address / City / Province / Postal code		Amount	☐ Cash ☐ Cheque

First name	Last name	Email address	Phone number
Address / City / Province / Postal code		Amount	☐ Cash ☐ Cheque

First name	Last name	Email address	Phone number
Address / City / Province / Postal code		Amount	☐ Cash ☐ Cheque

First name	Last name	Email address	Phone number
Address / City / Province / Postal code		Amount	☐ Cash ☐ Cheque

Tax receipts will be automatically issued for donations over \$20.
Tax receipts will be mailed by February 28th, of the following year.
Tax receipts cannot be issued if information is incomplete.

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Our sponsors



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ON THE ROAD

To a Cure

What are you fundraising for? For Kurt Luchia of Melfort, SK, it's his father, Perry. Before his passing in 2016, Perry was a part of the Canadian Armed Forces as an airplane technician and later a pilot. At the age of 40, he was diagnosed with Parkinson's disease and retired not long thereafter. Perry lived with Parkinson's for over 17 years, and in that time, restored a 1956 Willys Jeep with his son, "I hold many memories from these times and a lot of life lessons from working closely with someone with the disease" says Kurt.

On July 14 in honour of Perry and the special times he spent with his son on this project, Kurt Luchia will be driving the restored Jeep from his hometown of Melfort to Moose Jaw, where his father was posted with the Armed Forces. What would normally be a ~ 4hour drive with modern vehicles is expected to take the classic car almost double that.

Kurt will be collecting donations for his unique fundraiser on his SuperWalk team page, "Jeep Cruise for Parkinson's", where he's set an admirable goal of \$3,000 to go towards helping Parkinson Canada be there for Canadians living with Parkinson's today—while funding research into better treatments and one day, a cure.



Find a ParkinsonSuperWalk Near You!

Swift CurrentSeptember 1

Riverview Village Estates
Registration: 9:30am - 11:00am

SaskatoonSeptember 9

Meewasin Park North, off of Spadina
Registration: 11:30am - 12:30pm

Moose JawSeptember 8

Wakamow Valley - Kinsmen-Wellesley Park
Registration: 12:00pm - 1:00pm

ReginaSeptember 15

The South Leisure Neighborhood Centre
Registration: 11:00am - 1:00pm

** More walks to come, stay tuned!



Thank You!



Inspired Movement

Parkinson's Education Conference

April 27-28, 2018 | Saskatoon Inn  Parkinson Canada

When you think 'education conference,' what comes to mind? Too often conferences end up being long-winded, boring, and leaving the audience antsy to get out of their chairs; but for those that attended this year's Inspired Movement Education Conference, it was anything but boring. The event featured three presenters, each of whom took a different approach to physical fitness. Fran Gilboy of Regina, Jessica Lewgood of Estevan, and Adrienne Vangool of Saskatoon were not only chosen for their in-depth knowledge of the physical needs of people with Parkinson's but also to demonstrate the wide availability of services available right here in Saskatchewan.

Fran Gilboy kicked off the weekend with a dance class unlike any other. Fran led the 'class' through a program focused on big movements intended to improve symptoms of rigidity and stiffness. Many participants were unsure of what to expect, but even the least likely of dancers enjoyed expressing their creativity in the name of therapy.

After a powerful video by Janice Boucher and her para-reigning challenges and successes, we welcomed **Jessica Lewgood**, the weekend's keynote speaker, to the stage. Jessica spoke about the research behind

Parkinson's-specific exercise and the importance of purposeful movements. She walked through a sample exercise program that could be taken home, with specific movements for flexibility, balance, gait retraining, and more.

Adrienne Vangool of Vangool Wellness also joined us on Saturday to share her experience with Yoga as a form of complimentary Parkinson's therapy; even drawing on content from other presenters to bring the information full-circle. Adrienne demonstrated how yoga could be used for both mental and physical wellness, as well as how to modify certain movements depending on your abilities.

We closed with a panel of true Parkinson's experts: the people who live with Parkinson's every day. Drawing on the experiences of both caregivers and people diagnosed with Parkinson's, these motivating individuals shared how they stay inspired through movement.

If you missed out on the conference, there's no need to worry! The speakers' presentations will soon be posted to the Parkinson Canada YouTube channel, as well as the Parkinson Canada - Saskatchewan Facebook page.





Frédérique Larroquette
McGill University
\$30,000 grant over 2 years

Researchers who have devoted their careers to finding the cause of Parkinson's disease have, collectively, identified three major drivers of the death of dopamine-producing brain cells. They know clumps of a protein called alpha-synuclein, damaged mitochondria – the organelles that produce energy in cells – and misfiring neurons that disrupt electrical signals are all culprits that contribute to Parkinson's disease.

But scientists still don't know how these three culprits are linked, and why dopamine-producing neurons are the only type of brain cells so vulnerable to these stressors.

"We have three pieces of the puzzle, and we're trying to fit them together," says Frédérique Larroquette, a PhD candidate at McGill University.

Larroquette, a biomedical engineer, has decided to study neuroscience as well, to dig into the cellular functions causing this puzzle. Using stem cells derived from humans, she is transforming them into dopamine-producing neurons in cultures to mimic the activity in the human brain.

By studying the genetic mutations known to cause Parkinson's, including mitochondrial damage within the cells, the behaviour of alpha-synuclein and defects in the electrical activity of these cells,

Larroquette hopes to find answers to how all these things fit together to cause Parkinson's.

"It would be incredible if I could find the link between all three, because that's the million-dollar question," Larroquette says.

"It's really important to identify where the whole cascade starts, so that we are able to stop it," she adds.

If Larroquette can discover the initial defect or disrupted process that ends in Parkinson's disease, that finding could influence the design of new drugs or treatments, she says.

Ultimately, her goal is to marry her background in bioengineering with her research skills so that she can design new drugs and therapeutics.

Although Larroquette does not personally know anyone who has Parkinson's, she considers herself fortunate to have attended a Parkinson's walk last year where she met and interacted with people who are affected.

Now, she's doing her best for the people she met who are living with this disease.

"I'm hopeful – we are at a period of time where there are so many new and cool tools that are being developed especially with the stem cells because we now have a human model of the disease," she says.

"Through the efforts of a lot of people studying this, I think we're probably going to be able to put the puzzle back together at some point."

Read about other researchers recently funded by the Parkinson Canada Research Program by visiting the research section of our website at www.parkinson.ca, or in our monthly e-Parkinson Post newsletters at www.parkinsonpost.com.

In Memoriam

We offer our sympathy to the families, friends and communities who have lost loved ones over the past months, and we extend our sincerest thanks to those who have donated in their memory.

Melvin Byblow
David Goertzen
Leonard Callander
Allen Freethy
Floyd McHattie
Joe Wallsier

Hellen Brandt
Eileen Erickson
Marjorie Thesen
Gail McEwen
Irene Ward

*Those we love remain with us,
for Love itself lives on.
Cherished memories never fade,
because a loved one is gone.*

*Those we Love can never be,
more than a thought apart.
For as long as there is memory,
they'll live on in our heart.*

WHAT'S

NEW

@



Parkinson Canada



Before travelling this summer, be sure to check out Parkinson Canada's newest resource: **Parkinson's Disease & Driving**; complete with a driving skills assessment, red flags to be aware of, tips for improving your driving skills, and more!

Interested? Stop by our office for a copy, request a mail-out, or find it online at:

www.parkinson.ca/resources/educational-publications/.



Stay up to date on upcoming events, the latest Parkinson Canada news, and helpful tips and tricks for managing your Parkinson's!

<https://www.facebook.com/parkinsonsaskatchewan/>



9

Lows in Motion
Shakers to Date

7.5K

Total Attendees
Over 9 Years

\$550K

Raised for
Parkinson Canada

0

Fundraisers More Fun
than Lows in Motion

“Leading the Charge Against Parkinson’s”



NOV
03

SAVE THE DATE! November 3, 2018 @ 6:45PM

Don't miss out on one of the most entertaining nights of 2018. Join us for Canada's most attended Parkinson's Fundraiser! A night of laughter, dancing, and socializing, all for a great cause!



 LowsInMotion.com

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 [@LowsInMotion](https://www.instagram.com/LowsInMotion)

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