

PRC | Year-in-Review

PARKINSON RESEARCH CONSORTIUM

APRIL 2017



In this issue:

PAGE 2
IPCN

Celebrating Progress
in PD Research

PAGE 3
FUNraising for PD

PAGE 4
Living with PD:
Shelby Hayter's story

QUICK FACTS

- Parkinson's disease is a devastating neuro-degenerative disease
- Parkinson's disease affects 1 in 100 people over the age of sixty
- The exact cause of the disease is unknown
- The disease was discovered almost 200 years ago and still today there is no cure or proven treatment available

A message from our Co-Directors

April is Parkinson's Disease Awareness Month!

Over the past year, the ambassadors of the Parkinson Research Consortium (PRC) have continued to go above and beyond to raise awareness and funds in our community. These efforts directly impact our ability to conduct leading edge research into causes and possible treatments for Parkinson's disease.

Our most exciting initiative, directly resulting from funding support, is the Integrated Parkinson's Care Network (IPCN). This initiative coordinates and provides the best and most appropriate hospital and community resources for the personalized needs of

each patient, while at the same time producing valuable clinical data. Healthcare plans are designed by a neurologist and overseen by a nurse coordinator who links patients to the appropriate services personalizing patient care.

In the pages that follow we'd like to highlight the success of our research initiatives, showcase achievements by our young scientists and recognize our committed volunteers who tirelessly support our Parkinson's community by being the champions of the cause.

On behalf of all us, whether you are living with Parkinson's, a caregiver, volunteer or working behind the scenes in finding a cure for this debilitating disease...

We thank you!



Going Above & Beyond!

**Special Thanks to
Audrey Grant and
David and Jill Hogg for
always going above and
beyond for Parkinson's!**



Dr. David Grimes



Chief of Neurology, Director of the Parkinson's Disease and Movement Disorders Clinic, The Ottawa Hospital, Co-Director Parkinson Research Consortium



Dr. David Park



Director, uOttawa Brain and Mind Research Institute, Co-Director, Parkinson Research Consortium, Professor, University of Ottawa

Integrating Parkinson's Care Network (IPCN)



The IPCN 'one stop' approach was carefully designed to meet the unique needs of each Parkinson's patient through orchestrating all aspects of care, spanning from drug therapies to community-based services.

In fact, the IPCN ensures that patients get the best, and most comprehensive, care possible in timely manner.

The implementation of the IPCN approach at the Parkinson's disease and Movement Disorders Clinic in Ottawa begun in 2016 and already shows remarkable results! Within one year, IPCN achieved ten fold increase in patients' access to health care professionals and made dramatic differences in PD patients'

lives including substantial increase in autonomy and quality of life.

Just as one example, one of the patients at the clinic who previously spent most of the day in bed is now mobile and active.

In fact, 75% of IPCN patients reports that their condition had significantly improved. Indeed, in the little time since its launched the IPCN initiative changed many lives for the better!



Celebrating Progress in Parkinson's Research As part of Brain Health Awareness Week 2016

2016 Parkinson Research Consortium Fellowship Awardees

Crabtree Family Fellowship (\$30,000)

Awarded to: Bojan Shutinoski (post-doctoral fellow)

Title: Thinking Outside of the Brain: LRRK2 and Inflammation **Mentor:** Dr. Michael Schlossmacher

Toth Family Fellowship (\$15,000)

Awarded to: Brad Mischuk (graduate student)

Title: Harnessing Glutamate and Dopamine Receptor Crosstalk in Parkinson's disease and L-DOPA Induced Dyskinesia **Mentor:** Dr. Mario Tiberi

Audrey Grant Parkinson's Research Fellowship (\$15,000)

Awarded to: Mark Akins (graduate student)

Title: Filling gaps in alpha-synuclein related dementias: Identifying critical biomarkers of cognitive conversion in the sphingolipidome **Mentor:** Dr. Steffany Bennett

Bonnie & Don Poole Parkinson's Research Fellowship (\$15,000)

Awarded to: Khang Loc Duy Hua (graduate student)

Title: Role of Wnt/ β -catenin Signalling in Adult Zebrafish Dopaminergic Neuron Regeneration **Mentor:** Dr. Marc Ekker

2-year Fellowships

Shelby Hayter Fellowship (\$15,000 for 2 years)

Awarded to: Zachary Dwyer (graduate student)

Title: Inhibition of the CSF-1 receptor in LRRK2 G2019S mice to investigate the CX3CR1 pathway in an environmental toxin model of Parkinson's disease **Mentor:** Dr. Shawn Hayley

Larry Haffner Fellowship (\$15,000 for 2 years)

Awarded to: Chao-Chia (David) Lu (graduate student)

Title: Real-time identification of subcortical structures during deep brain stimulation surgery **Mentor:** Dr. Adam Sachs

The FUN in fundraising!

In the past year, the following community events were successfully organized by our many volunteers and all the funds raised went to support our scientist trainees and development of better integrated personalized strategies for our Parkinson's patients.

In 2016 these events raised:

- October 23: **Parkinson's Benefit Concert** at Greenfield's Pub raised over \$10,000
- March 23: **Audrey Grant's Better Bridge Event** raised over \$20,000 and
- June 19: **Lap the Gats for Parkinson's** raised close to \$94,000

SAVE THE DATES

2017: **Benefit Concert - Oct 22**

2018: **Audrey Grant - April 10**



David Park, Audrey Grant,
Julie Fiala, Steffany Bennett



Very special thanks to Audrey Grant who gives of her time year-after-year and Dave and Jill Hogg who lead the planning of the benefit concert who together have raised over \$120K for Parkinson's disease research!

GREAT RIDE



supported by

NOKIA

GREAT CAUSE

Lap the Gats for Parkinson's, our annual fundraising cycling event to help raise awareness and funds for Parkinson's research, was held on

Lap the Gats for Parkinson's

June 19, 2016 in the beautiful hills of Gatineau Park in Chelsea, Quebec.

The event took place on the 21 km loop and attracted over 300 riders, supporters and volunteers who together raised close to \$94,000.

The event is designed for cyclists of all levels. Participants seeking a challenge competed for Fastest Cyclist and Overall Hill Climber in

male and female categories. A King and Queen were also awarded the coveted yellow jersey for Fastest Cyclist and a red and white jersey for Overall Hill Climber.

Our next event is taking place June 25, 2017 as part of NOKIA Sunday Bike Day in cooperation with the NCC.

We are always looking for volunteers and of course riders to participate!

Registration is NOW OPEN!

lapthegats.org

Join Us!

Together we can lap the gats to find a cure!

Innovation means extraordinary treatment



Shelby Hayter
Photo credit Trevor Lush

Shelby Hayter ran the Boston Marathon in 2005. A month before, she was diagnosed with early onset Parkinson's disease. Within a few years, she could no longer run...

Her neurologist Dr. David Grimes explained a year ago that she had almost reached the end of the Parkinson's medication regime. He suggested the next step was deep brain stimulation surgery where electrodes would be implanted in her brain, providing regular electrical pulses to help control the disease's tremors.

"I felt at the end of the line, it was a last desperate attempt," Shelby said.

Shelby was assessed and considered a candidate for deep brain stimulation surgery. On October 18, 2016, during an eight-hour surgery micro-electrodes were implanted in Shelby's brain. She was awake for 90 percent of the operation. Three weeks later, she had a long involved second part of the procedure when the neurostimulator in her upper right chest was turned on, and the doctors started to determine the optimum balance between the stimulator voltage and her Parkinson's medication.

Six months later, Shelby is doing well. Her tremors are under control, the stiffness reduced, and she looks and feels younger. Shelby might even wear a red, sparkly dress again.

Written by Season Osborne

Shelby Hayter ran the Boston Marathon in 2005. A month before, she was diagnosed with early onset Parkinson's disease. Within a few years, she could no longer run.

Walking became difficult, as her left foot began dragging. Tremors in her hands made zipping up her coat, and holding a glass without spilling difficult became difficult. She'd be seized with rigidity and stiffness. At times, her left hand would become a claw. The disease was slowly taking away her mobility.

"Instead of wearing a red, sparkly dress, I would wear beige so I wouldn't attract attention. Before Parkinson's disease, I was among the life of the party," said Shelby.

For 11 years, the standard Parkinson's medication helped take the tremors away and lessened the symptoms. But gradually the treatments became less effective.

WE ARE VERY GRATEFUL FOR THE SUPPORT OF OUR ESTEEMED ADVISORY BOARD OF DIRECTORS

Richard Shantz, Chair

Tom Belton, David Cork, Rob Gibson, David Grimes, MD, John Hamilton, Robert Hanlon, David Hogg, Shelby Hayter, Nick Kaethler, Deanna Monaghan, David Park, PhD, Bea Robertson, Michael Schlossmacher, MD, PhD, Ian Toth