

PRC | Year-in-Review

PARKINSON RESEARCH CONSORTIUM

APRIL 2016

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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 Parkinson Research Consortium (PRC) has continued to successfully reach out to the Parkinson's community to raise awareness and funds that go directly to the advancement of innovative, leading edge research into causes and possible treatments for Parkinson's disease.

We would like to especially thank the **Partners Investing in Parkinson Research (PIPR)** group who this year raised \$140K at Ottawa Race Weekend to reach their goal of \$1M in seven years. **An incredible achievement!**



Dr. David Grimes



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

As a result of our PD community at work, we are excited to share our progress of the past year. 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.

One of these incredible individuals was Sharon Pickle who passed away on July 26, 2015. Sharon was an ambassador and great friend of the PRC. She was always willing to participate, volunteer and support us in any way she could. From conquering the challenge of cycling the Lap the Gats loop, and tirelessly volunteering

at events she will be greatly missed and her memory always cherished.



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!



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)

Integrated Strong
Parkinson's
Evidence Research Knowledge
Experts Improve Services Specialists
Survivors Personalized Health
Hope Progress Family
Committed Guidelines Connected
Team Independent Care-givers
Support Network Care

On September 14, 2015 as part of Brain Health Awareness Week the past year results of IPCN were presented by Dr. David Grimes.

This initiative will coordinate and provide 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.

We aim to personalize Parkinson's Care by integrating

healthcare options so that patients are connected to hospital and community services that treat all their motor and non-motor Parkinson's symptoms.

Healthcare plans are designed by a neurologist and overseen by a nurse coordinator who links patients to the appropriate services.

*Progress in
Motion: Integrated
Parkinson's Care
at Brain Health
Awareness Week
2015*

Progress in Motion—what we've achieved to date:

1. Identified a clinical care nurse coordinator,
2. Created an Access database that contains contact information for a comprehensive (>100) list of healthcare resources,
3. Established the parameters to monitor patient progress, health benefit and quality of life within this program.
4. Started enrolling patients in this program in July 2015!



Celebrating Progress in Parkinson's Research

The 2015 PRC Fellowship recipients were presented their awards at BHAW. The awardees include:

Crabtree Family Fellowship

Awarded to: Carolina Cieniak (post-doctoral fellow)

Title: Translational lipidomics: A new perspective on understanding and treatment of dementia with Lewy bodies, Parkinson's diseases and other neurodegenerative diseases.

Mentor(s): Dr. Steffany Bennett & Dr. Michael Schlossmacher

Toth Family Fellowship

Awarded to: David Lu (graduate student)

Title: Optimizing deep brain stimulation electrode placement by real-time identification of subcortical structures.

Mentor: Dr. Adam Sachs

Audrey Grant Parkinson's Research Fellowship

Awarded to: Jacqueline Tokarew (graduate student)

Title: Investigating the role of Parkin in oxidative stress mitigation and dopamine metabolism

Mentor: Dr. Michael Schlossmacher

Bonnie & Don Poole Parkinson's Research Fellowship

Awarded to: Kyle Farmer (graduate student)


Title: GM-CSF and CTEP as novel therapeutics in an early stage murine model of Parkinson's disease.

Mentor: Dr. Shawn Hayley



*Kyle Farmer receiving the
Bonnie and Don Poole
Fellowship award from
Mr. Ian Ewens*

4th Annual
Benefit Concert



6PM-10PM / 25.10.2015
Greenfield's Pub, Barhaven

Featuring **QUICKSAND**
with Opening Act **RACHEL HARRISON**

Celebrity MC
Terry Marcotte, Sports Director of CTV

Silent Auction and Raffle
All proceeds to Parkinson's Research

\$10 for Parkinson's Research Consortium

The FUN in fundraising!

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 2015 these events raised:

- Audrey Grant's Better Bridge Event raised \$12,750
- Annual Parkinson's Benefit Concert at Greenfield's Pub raised over \$6,500 and
- Lap the Gats for Parkinson's raised \$84,000



Audrey Grant, Megan Fitzpatrick, Michael Schlossmacher

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 \$90K for Parkinson's disease research!



Throughout the year, the PRC benefits from the tremendous work, time and energy of many in the community who want to help find a cure and a treatment to prevent the progression of this devastating disease and improve the quality of life of those suffering. In the past year, the



Lap the Gats for Parkinson's, our annual fundraising cycling event to help raise awareness and funds for Parkinson's research, was held on May 30, 2015 in the beautiful hills

Lap the Gats for Parkinson's

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 over \$84,000.

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 19, 2016 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!

Special Thanks to Bron Vasic

In recognition



Parkinson Research Consortium

Mr. Bron Vasic, Chair of the PRC Advisory Board - 2008-2014

In honour of Mr. Bron Vasic for his commitment as Chair of the Advisory Board of the Parkinson Research Consortium (PRC)

With your support the PRC has grown to the success it is today.

On behalf of the scientific leadership of the PRC, fellow Board members and our Parkinson community we thank you for your dedication and commitment to this important cause.

This past year we've welcomed Mr. Richard Shantz as new Chair of the PRC Advisory Board. Richard has been involved in Parkinson's Investing in Parkinson's Research (PIPR) and has a history working in the Parkinson's community. As we welcomed Richard we've also taken the opportunity to thank Bron Vasic, Past Chair for his years of commitment, support and

leadership of the PRC Advisory Board. Bron has been involved in the PRC since 2007 and was Chair for 5 years. He was integral in helping the PRC transition from startup to the success it is today. We are honoured that he continues to be a esteemed member of our Advisory Board.

Thank you Bron!



Richard Shantz and Bron Vasic

Levodopa pump gives new life to Ottawa Parkinson's patient



Nick Kaethler

Retired teacher Nick Kaethler, 75, was the first person in Ottawa to receive a newly approved treatment for advanced Parkinson's disease that delivers drugs directly to the small intestine. He says the pump has reduced his symptoms and given him back his life.

After 17 years of living with Parkinson's disease, 74-year-old Nick Kaethler was ready to give up the ghost. In the advanced stages of Parkinson's disease, the retired teacher could no longer walk unaided or hold a conversation, and the pills he took weren't working consistently anymore. So the man who had directed 20 choirs, spent four years travelling North America by motorhome and three years teaching English in China, planned a cruise with his wife June, certain that it would be his last.

But life had other plans. In 2015, Kaethler became the first person in Ottawa to use the levodopa pump or Duodopa, a newly-approved treatment for advanced Parkinson's disease in Canada. The steady dose of levodopa gel delivered through a hole in his small intestine dramatically improved his muscle control, and after an hour Kaethler could walk on his own, something he hadn't been able to do in months.

"It was magic," said Kaethler. "I felt I could plan for the future. I had my life again."

While wearing the portable pump in a fanny pack makes bending over and playing some sports challenging, Kaethler says it's a small price to pay for having his life back.

"Levodopa is the oldest and the best drug for Parkinson's disease- the pump just administers it in a more efficient way," said Dr. Mestre, who is also an assistant professor at the University of Ottawa. "The levodopa pump has been widely used in Europe for over 10 years, and has continued to be effective over that time for patients with advanced Parkinson's disease."

His neurologist at The Ottawa Hospital, Dr. Tiago Mestre, is running the Duodopa program at the Ottawa Hospital, and says Kaethler's response to the levodopa pump was expected.

The Ottawa Hospital began offering the pump to patients with advanced-stage Parkinson's in early 2015, after it was approved by Health Canada and covered by provincial healthcare, in a joint effort involving Dr. Tiago Mestre from Neurology and Dr. Alaa Rostom from Gastroenterology.

Like deep brain stimulation, the levodopa pump is an option to consider once pills become ineffective at treating the symptoms of Parkinson's disease. Dr. Mestre notes that the treatment is invasive and not for all Parkinson's patients, and those interested in learning more should speak to their neurologist or family doctor and consider a referral to the Duodopa program at The Ottawa Hospital.

While the levodopa pump relieves his symptoms for now, Kaethler doesn't know what new limitations may be on the horizon. Today he's grateful to be able to attend concerts and social events, to win bridge trophies again and to be able to sing with his choirs.

"As I get weaker, I'm glad to see there are strong people out there



Nick and June Kaethler

working on this," said Kaethler, whose doctor, Dr. Mestre, is part of the [Parkinson Research Consortium](#), a group of Ottawa researchers investigating mechanisms and new treatments for this devastating disease.

"Research is part of the business of finding life again."

Written by Amelia Buchanan