



The Ottawa  
Hospital



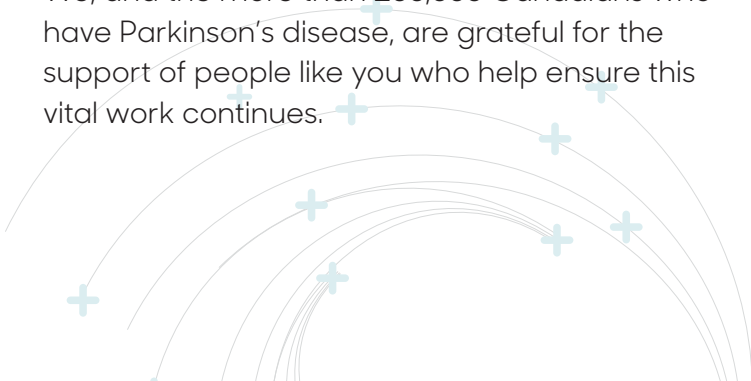
**UPDATE 2018-2019**

## **Piecing together the Parkinson's puzzle**

The Ottawa Hospital is an internationally recognized centre of excellence for neuroscience research and care. We have more than 400 scientists, clinician investigators, trainees and staff conducting ground-breaking research to understand how the brain works and to develop better ways to treat diseases like stroke, Parkinson's, multiple sclerosis, and neurodevelopmental disorders. This essential research is not federally or provincially funded. We, and the more than 100,000 Canadians who have Parkinson's disease, are grateful for the support of people like you who help ensure this vital work continues.

## **International Phase 2 trial for Parkinson's dementia treatment**

Dr. Chantal Barrett, Neurologist at The Ottawa Hospital, is working with researchers from three other countries to evaluate a novel dopamine receptor (D1) enhancer as a potential treatment for Parkinson's disease (PD) dementia. We are one of only four centres in Canada participating in this international Phase II clinical trial to assess the safety and effectiveness of the compound in patients. The study will enroll 340 patients worldwide with mild to moderate PD dementia with the ultimate goal of improving concentration, cognition, motor function and wakefulness.



Although the exact cause of PD dementia is not yet fully understood, it is generally caused by a significant loss in brain function as a result of changes in the structure and chemistry of the brain. It is characterized by symptoms that occur more than a year after problems with movement begin and include difficulty with memory and thinking that are advanced enough to interfere with daily activities and quality of life. It is estimated about 30 percent of Parkinson's patients will experience some form of dementia.



Dr. David Grimes

## Global study of early Parkinson's with specific genetic mutations

Dr. David Grimes, Chief of the Division of Neurology at The Ottawa Hospital is a principal investigator on a Phase 2 trial investigating early-stage Parkinson's disease (PD) patients carrying a specific glucocerebrosidase gene (GBA) mutation. We are one of only two Canadian sites, participating. As a result of earlier and ongoing genetic studies, The Ottawa Hospital has one of the largest recent cohorts of patients with these mutations of any centre in North America. The objective of this trial is to slow disease progression in patients with this subtype.

If the results are positive, this trial which takes place in 15 countries will change how Parkinson's patients worldwide are screened as part of routine care.

## High satisfaction in preliminary results of Phase 2 trial of integrated care program

Since 2015, Dr. Tiago Mestre, movement disorder specialist and neurologist at The Ottawa Hospital, Dr. David Grimes, and their team, have been developing the Integrated Parkinson's Care Network (IPCN). IPCN is a patient-centred model of care based on the concepts of care integration, patient empowerment, and personalized, technology-enabled care.



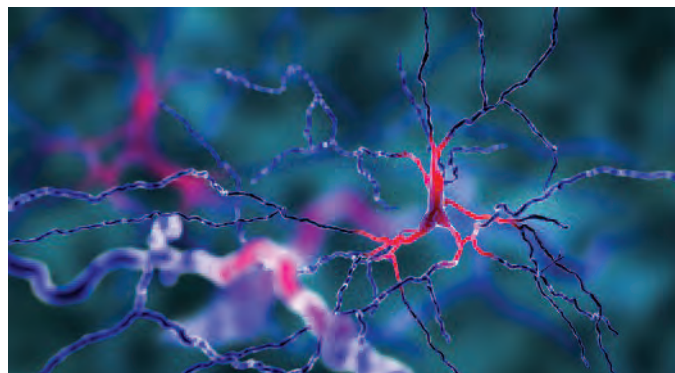
This model puts patients in charge of the day-to-day management of their disease. It pairs them with an easily-accessible expert nurse who helps them mitigate their non-motor symptoms and find external resources to ensure they live well with Parkinson's. This model has the potential to greatly improve patient care with little additional cost by breaking down silos across our health-care system.

Recently, Dr. Mestres received a \$197,000 New Investigator Award from the Physicians' Services Incorporated Foundation to launch a Phase 2 pilot study to evaluate this new model. Using this funding, in addition to support from the Leslois Shaw Foundation, the team recruited 100 eligible Parkinson's patients over six months in early 2018. By August almost half had completed the study. Early results indicated that among this group, 95 percent were satisfied with the IPCN experience. By the end of

November all 100 patients had finished participating and the analysis of their experiences will be released in early 2019. Meanwhile, the team continues to refine the platform using feedback from focus groups that include dozens of patients, physicians and other health-care professionals.

## Working with international partners to broaden the reach of IPCN

The Integrated Parkinson's Care Network (IPCN) at The Ottawa Hospital has seen tremendous growth and success in its development. Thanks to seed funding from Leslois Shaw Foundation, uOBMRI and PSI Foundation, The Ottawa Hospital's Parkinson Research Consortium has received funding from the Canadian Institutes of Health Research (CIHR) to lead an international consortium intended to refine the IPCN and continue to develop its health technology platform (virtual PD coach) that will allow for patient self-education and online health tracking. The iCARE-PD international consortium has the participation of leading PD centers in various European countries, including Ireland, France, Germany, Spain, the Czech Republic, Italy and Portugal.



The loss of dopaminergic neurons, pictured above, is associated with Parkinson's Disease.

Set to begin in 2019, the iCARE-PD international consortium will receive a total of \$2.2 million CAD from six national granting agencies, including CIHR, to complete five projects over three years. At the end of this project, we will see an improved and expanded version of the IPCN deployed throughout Europe and Canada. "Each of the partners is working on a different piece and so this effort is really focussed on pulling everyone's expertise together and using it to move the platform forward," said Dr. Grimes, Chief of the Division of Neurology at The Ottawa Hospital. "Here in Ottawa, we've created the backbone with ways for patients to input data and get information from it."

"What we will end up with," said Dr. Mestre, movement disorder specialist and neurologist at The Ottawa Hospital, "is what we call a 'virtual PD doc' that can take information from any technology, like an iPhone or a wearable, and plug it in to help patients with Parkinson's manage their disease."

As the platform expands and further studies are completed, Drs. Grimes and Mestre believe it will one day be able to predict the onset of some symptoms or imminent events, like falling, and will be able to provide proactive advice and solutions tailored to each patient, anywhere in the world.

## Diane Côté: a spotlight on one of our champions



As our Parkinson's team works to develop the technological side of the Integrated Parkinson's Care Network (IPCN) platform they will focus on enhancing the more automated, or passive, aspects of information collection and distribution; but for their proof of concept pilot study, the linchpin of its success has been a decidedly more human one - the expert Parkinson's nurse who interacts with our study subjects, Diane Côté.

Diane has been working with Parkinson's patients for more than a decade and has been involved in the development of the IPCN as the coordinator since it began in 2015. Patient after patient says she has been an invaluable and tireless resource for all aspects of care. She has become their teacher, their friend, and their champion, and after seeing first-hand the difference the IPCN has made in their quality of life, is convinced this is a critical piece of the care puzzle for Parkinson's patients.

With the IPCN pilot study wrapping up, Diane is looking forward to the next stage in the development of the platform which will include apps and wearable devices that will afford access to even more information, provided in real-time. Undaunted by the challenge of parsing so much new data, Diane, instead, is inspired. "Our patients are so courageous, and I just want to keep them as well and as active as I can. I tell them you might not have wished for this, but we are going to figure out a way to live a good life, to live well with this. We're not gonna let it win."

## Making a difference through leadership

In September of 2018, Dr. Michael Schlossmacher, Director of the Neuroscience Program at The Ottawa Hospital, took on the role of Interim Director of the University of Ottawa Brain and Mind Institute. He said he hopes to help The Ottawa Hospital and the University of Ottawa “advance the goal of creating a flagship centre at the new Ottawa Hospital Campus” until the search for a new Director is complete.



Dr. Michael Schlossmacher

## Celebrating 10 years of extraordinary philanthropy

About a decade ago, several local investment advisors were struck by how many people close to them had been affected by Parkinson’s Disease. Knowing firsthand the effects of this relentless neurodegenerative disease, they were determined to make a difference and established Partners Investing in Parkinson’s Research (PIPR) to support Parkinson’s research at The Ottawa Hospital. Their original goal was to raise \$500,000 in five years but they surpassed that in just three. Today, the PIPR group counts more than 20 people among its core members with hundreds in their network and has raised more than \$1.32 million.



Team PIPR celebrating 10-years of Partners Investing in Parkinson’s Research at Tamarack Ottawa Race Weekend 2018.

Over the last 10 years, this important funding, combined with other community support has not only enabled our researchers to leverage additional research funding from other sources, including granting agencies like the Michael J. Fox Foundation and the Canadian Institutes of Health Research, but has also contributed to the:

- funding of basic science and translational research projects through named scholarships. Since 2009, more than 35 trainees have been supported.
- recruitment and start-up of some of the world's leading scientists working on Parkinson disease including Dr. Tohru Kitada from Boston, Dr. Adam. Sachs from Stanford University, Dr. Tiago. Mestre from the University of Toronto, and most recently Dr. Max Rousseau from University of Baylor (Texas).
- establishment of the Deep Brain Stimulation program at The Ottawa Hospital, bringing an entirely new platform of surgical therapy to our patients here in Ottawa.
- launch of the Integrated Parkinson Care Network (IPCN) to provide integrated care for our patients that coordinates all related discipline.
- financing of new equipment that allowed new technologies and projects to be developed here in Ottawa including the purchase of a mass spectrometry instrument that put The Ottawa Hospital at the international forefront of lipid analyses.
- improved profile of Parkinson's research in Ottawa. PIPR has galvanized the community to support a cause that previously received little attention. But perhaps more importantly than anything else, the PIPR team has given much-needed hope to those who live with this unremitting disease.

## Dr. Julianna Tomlinson's ground-breaking gene research

Mutations in the glucocerebrosidase gene (GBA1) are the most common genetic risk factor for Parkinson's disease worldwide. Dr. Julianna Tomlinson, Senior Research Associate at The Ottawa Hospital, and her team will study how these mutations contribute to Parkinson's and what effect they have on the course of the disease or its outcomes. There is already a lot known about the GBA1 gene because mutations in both copies of this gene cause Gaucher disease, a rare illness but one for which a number of treatments have already been developed.



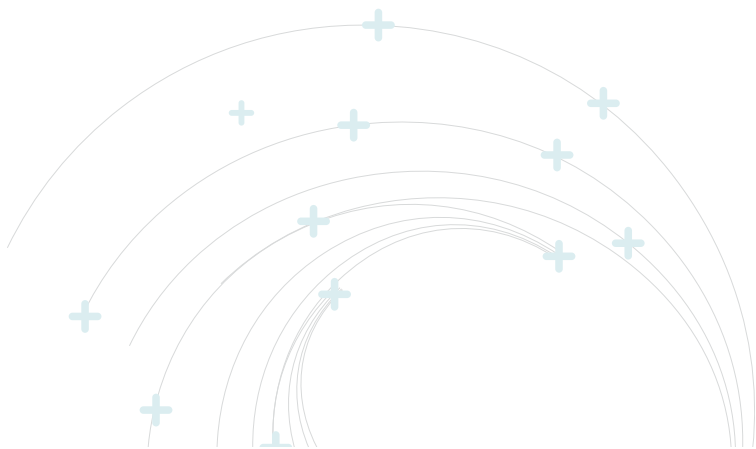
Dr. Julianna Tomlinson

"What is exciting is that we can take what we already know about GBA1 and Gaucher disease and see if the drugs that are used to treat the disease have potential for treating Parkinson's," said Dr. Tomlinson. "It's promising and brings us steps closer to a treatment."

Every year since the PIPR group surpassed their original \$500,000 goal, they have chosen to support a signature research project that shows great promise in advancing our understanding of Parkinson's disease. This year, the group has chosen to help fund Dr. Tomlinson's work.

To read more about Dr. Tomlinson's research please visit:

<http://ohfoundation.ca/our-supporters/dr-julianna-tomlinson>



## Let's Talk Parkinson's

After originally being frozen out by an unwelcome ice storm, our annual Let's Talk Parkinson's event was a resounding success just a week later, on April 23.

An all-star panel of Ottawa physicians and researchers shared the latest developments in Parkinson's research and treatment with a capacity crowd of more than 220.

A lively question and answer session followed presentations by:

- Dr. David Grimes, Chair/Chief, Division of Neurology, The Ottawa Hospital
- Dr. David S. Park, then Director, University of Ottawa Brain and Mind Research Institute
- Dr. Michael Schlossmacher, Director, Neuroscience Program, the Ottawa Hospital Research Institute
- Dr. Tiago Mestre, Movement Disorder and Parkinson's Specialist, Division of Neurology, The Ottawa Hospital

If you're considering joining us for the 2019 edition of Let's Talk Parkinson's, mark Tuesday, April 9 from 5:30pm – 8:00pm. on your calendar now!



Drs. David S. Park, David Grimes, Tiago Mestre and Michael Schlossmacher, our panellists for Let's Talk Parkinson's 2018

## Thank you, your generosity is saving lives in Ottawa

You are a critical part of our success.  
Thank you for your tremendous support.

The Ottawa Hospital deals with the most challenging medical cases in the region, approaching each case with that unique mixture of medical excellence, practice, and compassion. Our calibre of research and patient care is attracting some of the brightest and most capable health-care professionals in the world who are helping us deliver world-class care to patients in our region.

We invite you to continue this important journey with us as The Ottawa Hospital transforms Parkinson's disease research, and patient care in Ottawa and beyond.

For more information, please contact:  
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