



Celebrating Alberta's Innovations in Research



Investment in Alberta based Parkinson's research has been an integral part of the framework of Parkinson Association of Alberta for almost 15 years. Through the generosity of our community, we have been able to contribute more than \$1.5 million to the development of talented early researchers in Alberta. We thank you for your ongoing support of this important work.

In 2021, we reached out to our stakeholder groups to really understand the needs and priorities of our Parkinson's community. In addition to the programs and services we deliver, research was at the forefront. This learning exercise brought us to redefine our Guiding Principles and Strategic Priorities. Relating to research, Parkinson Association of Alberta aims to "Provide meaningful engagement in quality-of-life research through participation, education and collaborative fundraising efforts."

What does this mean?

- 1** Parkinson Association of Alberta is a conduit for communication and engagement between researchers and people living with or caring for someone with Parkinson disease or Parkinson's Plus Syndromes. We hear really incredible feedback from those in our community who choose to participate in research activities. There is validation in contributing to improving future outcomes, options, treatments and understanding.
- 2** We are committed to bringing excellence in education relating to research through regular webinars, our annual Hope Conference, and features like this one.
- 3** We work with our Alberta research community as well as like-minded organizations across the country to bring awareness to Parkinson disease in order to inspire financial investment. Your choice to invest in research through Parkinson Association of Alberta helps create capacity in our PD research community.

In this special research addition to Pulse, you will meet some of the incredible individuals working in Alberta's PD research community and in Parkinson's health care, including Dr. Oksana Suchowersky. Dr. Suchowersky has been helping to guide the activities of Parkinson Association of Alberta for over 20 years in various roles and has chosen to step back from our Board of Directors following May's Annual General Meeting. I am personally grateful for her wise guidance and ongoing commitment to remain involved with PAA as a volunteer.

Thank you to each of our presenters through April's Parkinson Awareness Month, for sharing your knowledge and time with our Parkinson's community and for the work that you do.

100% of donor contributions to PAA designated to research, flow directly into fostering talent locally. Please consider investing in the future of Parkinson disease research in Alberta.

Sincerely,

A handwritten signature in dark ink, appearing to read "Lana Tordoff". The signature is fluid and cursive, written over a light blue geometric pattern.

Lana Tordoff, *Executive Director*

RESEARCH COMMITTEE

Martin Kratz



Martin Kratz is a professor, author and retired senior technology and intellectual property lawyer. He has worked for a time as a research manager and also served on the board of directors of a stem cell company that was engaged in research on use of stem cells for many neurological disorders.

Born in Alberta, Martin is the current Board Chair of PAA and has extensive board experience, having served as chair, in a governance committee role and as a director on numerous boards. Martin has also served on numerous charitable boards.

Dr. Oksana Suchowersky, MD FRCPC FCCMG

Dr. Suchowersky has almost 40 years experience looking after people with Parkinson disease. Her career started at the University of Calgary's Faculty of Medicine when she was recruited to develop the Movement Disorders Program in 1984. Under her leadership, the program grew to an internationally recognized center for care of patients with Parkinson disease, and related movement disorders. In 2010, she was recruited to the University of AB to expand the Movement Disorders and Neurogenetics Programs. Her research interests include identifying genetic factors and developing new treatments for PD. She has published over 200 peer reviewed publications, and edited two books. Dr. Suchowersky is chair of the Research Committee.



Dr. Renee Misfeldt, PhD



Dr. Misfeldt has vast experience with applied health systems and policy research, and a comprehensive understanding of Canadian health policy. She is the assistant clinical professor with the Dept. of Family Medicine at the University of AB. Her experience is rounded out by employment as a senior health policy researcher with the think tank Canadian Policy Research Networks where she conducted client-based research for various organizations including Federal and Provincial governments, Canadian Nurses Assoc., the Health Action Lobby, and the Canadian Medical Assoc. Renee holds a PhD in medical sociology and an MA in sociology (criminology) from the University of Saskatchewan. She is also the author of over 50 publications, book chapters, and policy reports on Canadian health policy and systems and co-authored a book on Nunavut's healthcare system.

Dr. Cara Ferreira, PhD

Cara Ferreira received her PhD in medicinal chemistry and her MBA in strategic management from the University of BC. As a scientist she has lead research related to medical imaging including for Parkinson disease. In her current work in the pharmaceutical industry, Cara focuses on helping pharmaceutical and medical device companies positively impact patients' lives through the launch and growth of innovative products. Born in Calgary, Cara returned to her hometown in 2013 excited to be closer to her family. Soon after her return, her father was diagnosed with PD increasing her awareness of the often unseen challenges of living with the disease for the patients and their loved ones.





Dr. Oksana Suchowersky, MD, FRCPC, FCCMG

On behalf of the Board of Directors, staff and members of Parkinson Association of Alberta (PAA), we congratulate and thank Dr. Oksana Suchowersky for her more than 20 combined years of support and service to our Parkinson's community. On May 28, she will be retiring from her role as a board member with PAA.

Dr. Suchowersky has been part of Parkinson Association of Alberta since joining the Board of Directors in the early 90s (and re-joining in 2012). She has helped to grow the organization, showcase Alberta research and researchers, and promote the diversity and value of ongoing Parkinson research in Alberta. Dr. Suchowersky has invested her time, talent and significant knowledge to help educate our staff and community, plan meaningful educational events, and nurture and grow our commitment to research. Our Operations Manager, Brandi La Bonte, sat down with Dr. Suchowersky recently to chat.

Brandi La Bonte (BL): In preparing for our interview today I went back and looked at the very first interview you and I did together – which was back in 2015. Then I started thinking about how long you and I have known each other and realized you even pre-date me! When did your journey with Parkinson Association of Alberta begin?

Dr. Oksana Suchowersky (DOS): I first joined the Board of Directors in 1990 in Calgary when the organization was still known as Parkinson Society of Southern Alberta. It was a very small organization back then, run almost entirely by volunteers; but we were able to promote Parkinson's and raise money for research. I left the Board briefly when I was recruited to Edmonton and the University of Alberta. I was elected to the Board in 2012, and since then, I do think the organization has really grown.

Joining the two organizations (Parkinson Society

of Southern Alberta and Parkinson Alberta as each organization was respectively known in 2010) was important to promote Parkinson disease and Alberta and the work the organization is doing here. It's just gradually gotten stronger and more prominent.

BL: Would you say that as a Board Member, leading the development and growth of the research component of Parkinson Association of Alberta's mission has been a highlight?

DOS: As a Board Member yes, I think that is one of my highlights. Specifically, developing a research fund to fund **people** to do research. Parkinson Association of Alberta doesn't fund research projects, we fund the students that do the research – the bright young minds of tomorrow. It was our thought early on that once they (the researchers) have people in place they can get funding from other sources. And if we fund students, we encourage growth in the area of Parkinson's

research. This approach hopefully encourages the next generation of Parkinson's researchers, and also encourages current senior researchers who maybe haven't done much research in Parkinson's to be more interested in Parkinson's research.

BL: Do you think this strategy is working well? Have you noticed interest in Parkinson's research here in Alberta pick up?

DOS: Oh yes. I think the programs have grown at the universities; there are more people doing research in Parkinson's. And every year I get requests from researchers at the universities asking if this program is still running and whether there might be funding available. I think especially with funding from other sources, for example CIHR (Canadian Institute of Health Research), becoming harder and harder to obtain; then our (PAA's) funding is very important in getting researchers funded here in Alberta.

Since we started the research funding competition for students and post-doctoral fellows in 2015, we've funded a dozen or so students across Alberta to do research in Parkinson's.

BL: When you decided to join the Board 20 years ago and again 10 years ago in 2012, clearly your passion for and commitment to research was a big part of that; were there any other motivating factors for you?

DOS: I think it is just a commitment to people with Parkinson's. I've been seeing people with Parkinson's since 1984 and so it's the commitment to providing care to people with Parkinson's and their families and expanding the clinics to provide care. When I was in Calgary, I started the Deep Brain Stimulation (DBS) program – we were the first in the province to do so. And when I was in Edmonton, I started the Duodopa program – and again we were the first in the province to do so.

It is really about the provision of care, but also the expansion of services.

BL: I've heard that though you are retiring from the PAA Board of Directors that you are still wanting to be involved, can you elaborate?



DOS: Yes, I would like to stay as a volunteer with the Research Committee. The Research Committee is a large one and a very good one, and the person replacing me is also very knowledgeable. The people on the committee are all relatively new to the Board though so I would like to stay as a volunteer to help with the transition.

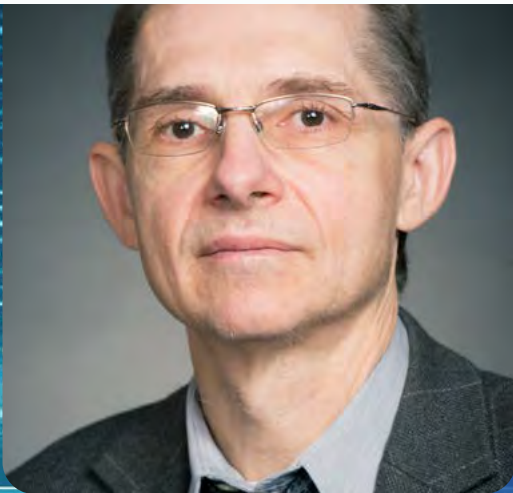
BL: On a slightly more personal note, you and I have known each other for a while now – through a lot of different organization names and change, but always in the service of people with Parkinson's. And I wanted to say it's been great. You have always been willing to help and answer questions. Not only for me, and of course our clients, but for our staff as well. You have educated us, explained things when we didn't quite understand and took the time to answer our questions so that we could better serve our clients. It has been an honor and privilege to get to know you and work with you over the years.

DOS: Oh, thank you. It has been great working with you and the Board and staff. I think things with the Board and with Lana are just really, really great.

BL: Thank you so much Dr. Suchowersky, and congratulations on 20+ years with Parkinson Association of Alberta.

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Dr. Richard Camicioli, MD, FRCPC



Dr. Richard Camicioli obtained fellowship training in geriatric neurology at Oregon Health and Sciences University, joining the faculty in 1994. He came to the University of AB as associate professor in 2000 and became full professor in 2008. His research interests include cognitive dysfunction in Parkinson disease and motor dysfunction, especially gait disorders in aging and dementia. He applies epidemiological genetic and imaging research methods to better understand clinical phenotypes and clinical outcomes.

Dr. Vikram Karnik, MD

Dr. Vikram Karnik completed medical school at the University of AB and following the completion of neurology residency training at the University of Calgary, he completed a fellowship in movement disorders at the Beth Israel Deaconess Medical Center and Harvard Medical School in Boston. He joined the faculty at the University of Calgary in 2021. Vikram works in the Movement Disorders, Urgent Neurology, and General Neurology clinics, and splits time between the South Health Campus, Foothills Medical Center, and Rockyview General Hospital.



Dr. Davide Martino, PhD, MD



Dr. Davide Martino is an associate professor and director of the Movement Disorders program at the Hotchkiss Brain Institute at University of Calgary. His research program focuses on biological markers, environmental factors and multidisciplinary pathways of care for complex movement disorders, mainly dystonia, Tourette syndrome, Parkinson disease and essential tremor.

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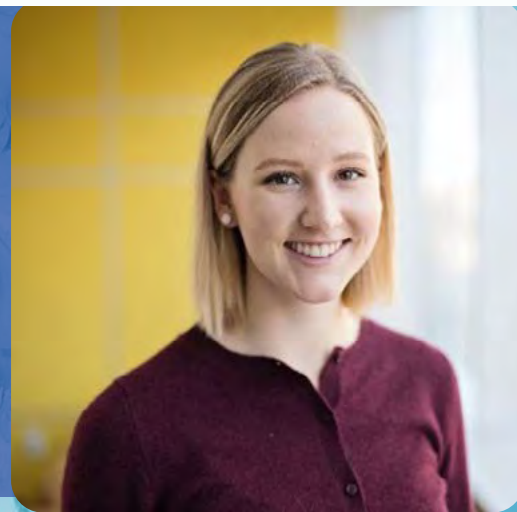
Dr. Allyson Jones, PT, PhD



Dr. Jones is a professor in the Department of Physical therapy with a cross appointment in the Department of Public Health Sciences. Her research interests are patient health outcomes and health-related quality of life in chronic musculoskeletal conditions common in elderly patient populations. Using multiple methods, including patient surveys, clinical evaluation, performance measures, and administrative databases, Dr. Jones looks at functional, health-related quality of life (HRQL) and health services outcomes to determine how we can maximize successful outcomes with total joint arthroplasty spinal stenosis and hip fracture.

Charlotte Ryder-Burbidge, MSc

Charlotte has an MSc in Epidemiology and a passion for empowering people with evidence-based health information. As a research associate, Charlotte supports the development and execution of research related to cancer prevention and survivorship. Her previous work focused on the health of older adults and people living with neurological conditions.



Kenneth Murdoch, MEd, RPsych



For the last decade, Kenneth has been a researcher at Hope Studies Central, a research lab dedicated to better understanding the experience of hope in human life. As a researcher, Kenneth focuses on listening for stories of hope in people's lives and is particularly interested in the pivotal role of hope in our overall physical and mental health. His recent research has focused on developing and evaluating positive psychology programs aimed at enhancing hope and emotional wellness for people with PD (PWP). He is also conducting research aimed at elevating the voices of PWP and better understanding the lived experience of hope for those newly diagnosed.

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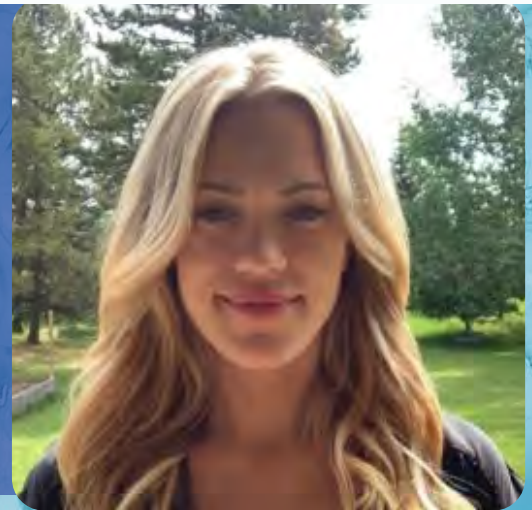
Dr. Veronica Bruno, MD, MPH



Dr. Veronica Bruno is a neurologist with a subspecialty in movement disorders. She completed her fellowship in Movement Disorders at the University of Toronto and a Master of Public Health degree at the Harvard TH Chan School of Public Health. Dr. Bruno's primary interest is the treatment of advanced Parkinson disease, with a particular research interest in the non-motor symptoms of the disease. She also has a special interest in Global Neurology and the search for innovative solutions to improve the quality of neurological care in low and middle income countries.

Dr. Jennifer Andrews, PhD

Dr. Jennifer Andrews received a PhD in Neuroscience in 2016 after completing a BSc at the University of AB. She later joined the Functional Neurosurgery Research Laboratory in 2017 as a post-doctoral fellow and is currently in her second year of medical school. Her research aims to develop a clinically useful biomarker of optimal therapeutic benefit from deep brain stimulation (DBS) in Parkinson disease.



Dr. Taylor Chomiak, PhD



Dr. Taylor Chomiak is a staff scientist and Adjunct Assistant Professor in the Department of Clinical Neurosciences at the Cumming School of Medicine, University of Calgary. Dr. Chomiak's research program is focused on adaptive sensorimotor rehabilitation, predictive modeling, and intelligent sensing. This includes developing integrated approaches using wearable / portable sensor technology and machine-learning-based approaches to better understand, prevent and manage complex cognitive conditions and movement disabilities in Parkinson disease. Together, his research will advance the use of low-cost portable technologies and the identification of digital biomarkers to aid in clinical decision support.

Thank you!

to our 2021 Research Donors

These valued supporters contributed at least \$1,000 for Parkinson's research in Alberta last year

- William Aaron
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How Are New Treatments For Parkinson Disease Developed

H. Shaikh, O. Suchowersky MD, FRCPC, FCCMG

Professor of Medicine (Neurology), Medical Genetics, and Pediatrics,
University of Alberta

The development of new therapies for Parkinson disease is fueled by research. This is a long and slow process, taking decades, and millions of dollars before a new drug can be used clinically.

It starts with preclinical trials to establish whether a treatment appears to be effective and safe, and to determine if further investigation is worth pursuing. Preclinical experiments include “in vitro” and “in vivo” trials. “In vitro” trials occur in the lab, using cells or tissues. These are followed by “in vivo” trials, done on animals. Following successful “in vitro” and “in vivo” trials, the study shifts to clinical trials, which are composed of three different phases.

Phase I

The first phase of clinical trials, Phase I, involves a few individuals with the goals of assessing the safety of the treatment, evaluation of any side effects, observation of the action of the treatment, including how it moves through the body, how the body responds, and how it is eliminated. If Phase I is successful, the study moves on to Phase II.

Phase II

Phase II is done with the objective of monitoring the benefits, tolerability, and safety of the treatment. Additionally, these trials are useful to establish the effective dosage. Every individual is unique and may react to different treatments differently, so it is helpful to observe the effects of the drug on a larger sample of people. Phase II trials may be done with two groups of people divided into experimental and control groups. The experimental group receives the actual treatment, while the control group receives a placebo, a “sugar pill”. The experiment is typically done with the study participants, investigator, and/or both being blinded; this means that they do not know who is receiving the treatment and who is receiving the placebo. This allows the researcher to observe the effects of the proposed treatment in an unbiased fashion.

Phase III

Phase III trials are typically done on a large number of individuals, usually several thousand. The purpose of this phase is to compare the new treatment to existing treatments or placebo to determine the benefits and safety. In order to ensure impartiality, Phase III trials are always done in a double-blind controlled fashion, meaning neither participant nor researcher knows who is on which treatment.

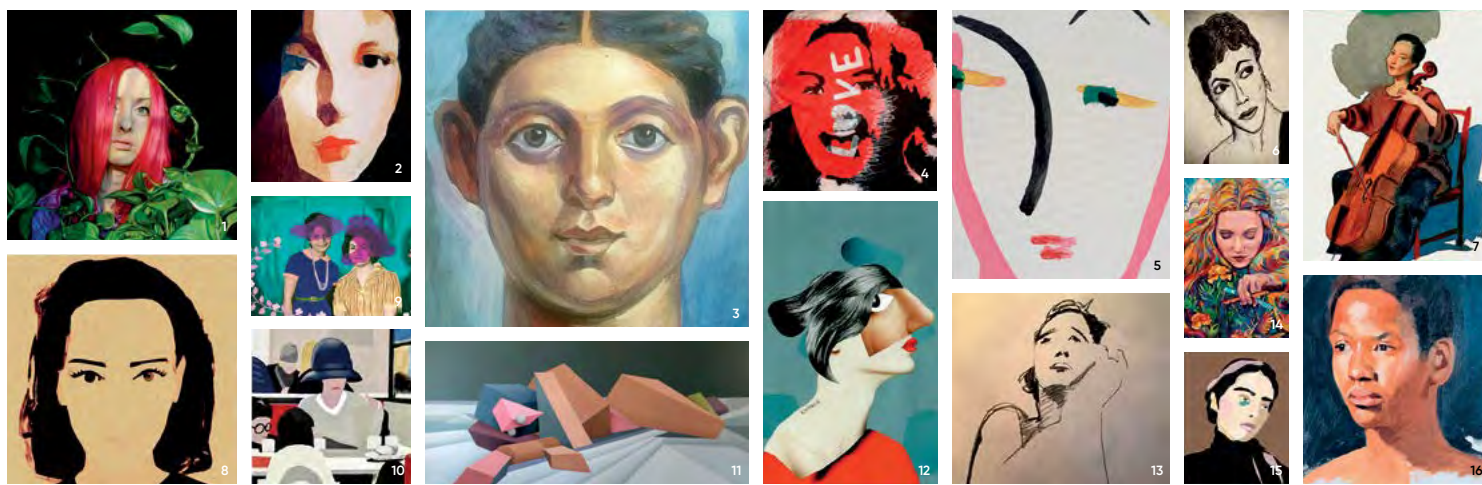
In the event that the treatment proves successful, approval is given by Health Canada after it reviews all of the data. Only then may it become available on prescription, but research does not end there.

Once the treatment is in widespread use, information continues to be collected by Health Canada, and the pharmaceutical company to monitor the side effects of the treatment.

All clinical research that is conducted must strictly adhere to ethical guidelines. Research must be conducted with informed consent, which means that potential participants are told about the study and permission is obtained from the participants before proceeding. Participation is entirely voluntary, and the participant has the right to withdraw from the study at any time. The researcher is obliged to minimize the risks associated with the study, in other words, they must protect the participants from harm. Additionally, researchers must be respectful of privacy and confidentiality by safeguarding the participant’s personal information.

Lastly, the participants are entitled to know the true purpose of the study, with as much information as possible being provided. Following study completion, the participants should be told whether they were on the study drug or a “sugar pill”.

Clinical research is a complex process that must adhere to strict scientific and ethical guidelines. With many potential candidates that can be studied scientifically for Parkinson disease, there is plenty of hope for the Parkinson’s community that new treatments will continue to be developed.



WE'RE ALL DIFFERENT AND THAT'S WHY THIS IS SO IMPORTANT.

Women are twice as likely to suffer from depression, dementia and stroke as we age. Yet most brain research hasn't studied the links between sex, gender and disease. It's time for new, more equitable perspectives. That's why Women's Brain Health Initiative is teaming up with Brain Canada to provide grants that help close the research gap.

All the art above was generously donated in support of this important cause. Our thanks to them. Should you want to contact or follow them on Instagram: 1. @DorisRoseArt 2. @SeanaDraws 3. @SoxBoots 4. @Gholme 5. @HowardAlstad 6. @Andy.Berlin 7. @JamesMcMullanArt 8. @SeanaDraws 9. @Daisy_Patton 10. @GeoffreyDraws 11. @JasonBoydKinsella 12. @Ewa_Look 13. @WinifredOffTheMat 14. @Jessica_A_McVicker_Art 15. @Chem.Laura 16. @Gholme



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