

THE FUTURE IS NOW

Perspectives on Parkinson's and Research

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For some of us, hearing the words “medical research” can make us want to run in the other direction. It can be too complicated, too abstract, too time consuming, or too far away to get excited or involved. However, for many others in our community, learning about and/or participating in research and advancing the understanding about Parkinson disease gives them hope.

In general, there are three ways people impacted by Parkinson's engage with research; by learning about it, by participating in research trials, or by donating to it. In this article, with perspectives and input from our clients, will dive into the first two – learning and participating.

Learning About Research

“As a person with Parkinson's I find benefit from the hope and optimism that research brings -- from new approaches to treatment, to genetics, to a better quality of life – even if the goal of the study is not to find a cure.”

The world of Parkinson's research is vast and exciting. Across the globe, and right here in our own backyard researchers are looking into various aspects of Parkinson's; from causality to cognition, from aspects of voice and exercise to treatment options, from the perspective of the person with Parkinson's to the impact on care partners, and everything in between. The depth and breadth of Parkinson's research can

be very motivating for some, but it can also be intimidating for others. Research topics can be complex and unrelatable, articles can be long and often written in a way that can make you feel like you're reading a foreign language. If, like me, you don't have a medical degree and a couple PhDs to boot, checking the dictionary or googling every new term, might not feel like a productive use of your time. And then, of course, there is trying to decipher what is honest-to-goodness, proper medical research versus some shady character just trying to hustle you on the internet.

So how does one begin educating themselves on Parkinson's research? A good place to start is figuring out what is important to you on your Parkinson's journey. Is it specific aspects of Parkinson's? Say cognition, gait, or exercise? Is it potential new treatment options on the horizon? Is it the more scientific perspective (causality, genetics, etc.)? Maybe its all the above. Once you determine your interests the next step is finding reputable sources of information. Research connected to federal

funding agencies like the Canadian Institutes of Health Research (CIHR) or the National Institute of Neurological Disorders and Stroke (NINDS – USA). Research conducted in association with universities (including our own universities of Alberta, Calgary, and Lethbridge among others). Research noted or shared by reputable Parkinson's patient organizations (such as us, Michael J Fox Foundation, Parkinson Foundation, Parkinson Canada, Parkinson's Europe, etc.). And for those who are interested in learning more about research but struggle with the scientific language; our clients often suggest their favourite trustworthy podcasts (i.e.: MJFF Parkinson's Podcast, When Life Gives You Parkinson's, The Parkinson's Podcast, etc.) that aim to break down these complicated studies and make it easier for the lay person to understand and digest. A podcast may invite a researcher or specialist to talk about their research, and the host is then able to break the information down and 'translate' if you will, so that anyone can understand the concepts, but the information is still coming from and being confirmed by a reputable source.

The internet can be a wonderful resource and has so much information available to us – but it can be hard to know which sources can be trusted. Some are fairly obvious; an article written by “Joe Schmoie” who believes Parkinson's is caused by alien life forms coming from Jupiter to alter our brain chemistry in our sleep is easy to identify as not credible. Some, however, aren't so easy to tell. For those who might be uncertain in their ability to navigate fact from fiction when it comes to research consider asking yourself a couple question:

- » Does this “research” promise to remove or reverse all symptoms or even cure Parkinson's?
- » Am I being asked to provide payment before you receive any information?

In this day and age where so many scams exist, especially online, it serves us well to be diligent, ask questions, and ask when we aren't sure. Hope is so important for morale, especially when coping with a progressive disease like Parkinson's, and sometimes we must use our media literacy skills to protect ourselves from those who want to prey on our optimism. A good rule of thumb is to note whether the article, website, or information has been studied, written, and

peer reviewed by named medical professionals and/or researchers who share their credentials. And, that this information is comparable to information that you already know is reliable. Checking on the latest and greatest research updates from reputable sources (as indicated earlier in this article) is key.

If you're ever unsure about something you've read or heard, or something seems 'too good to be true' it's a great idea to talk about it with a trusted member of your healthcare team (including Parkinson Association of Alberta staff).



Participating in Research Trials

Like learning about research, participating in research trials is an exciting opportunity for some and a “meh” for others. So why do people like to participate in research? The answer to this question is different for everyone.

Some clients tell us that participating in research has allowed them to regain some agency they felt the disease took away from them. “By participating in research studies, I feel like I am taking an active part in what is going on – not just letting Parkinson's happen to me.” Some, like care partners I spoke with, told me they encouraged their loved one to participate in research studies because they can offer the researcher an opportunity to reflect on what they've learned from participants, and it could potentially give their loved one a voice that would be considered when treating patients today and tomorrow.

I felt the reverence a care partner held for their loved one with PD when they were telling me how proud it made them to be the spouse of someone, who despite the adversity they were facing, still wanted to be involved in research in the hopes that looking at their brain might help future patients. "Participating in research gives me hope that even if this doesn't help me – somebody in the future might benefit and not have to go through all the challenges I've had."

For others, participating in research gives them a sense of purpose – "Keeping up to date on research and being an active participant, prevents me from sinking into apathy and lets me feel like my Parkinson's isn't defeating me." Another perspective brought forward was that participating in research instills a great confidence in the medical field and researchers of tomorrow. "Every time I go down to the University of Alberta, University of Calgary or even further reaches like UBC or the University of Cincinnati to participate in a study, I am left feeling we are in good hands. The (often) young researchers are always positive, friendly, kind, ambitious, patient and eager to make a difference in our lives and sometimes we see our neurologists in a different light outside of their office setting." Experiences like this can be a beacon of hope for the breakthroughs to come in Parkinson's research.

Finding the Balance

How does one balance the hope that research inspires with the realities of Parkinson's? Hope can be a tricky thing, especially when navigating a disease like Parkinson's. Too much and you might end up like the ostrich with its head stuck in the sand ignoring the realities around you. Too little, and life can feel very dark and, well, hopeless. In the end, it really is a balancing act. We need hope as much as we need reality. We need to believe in the possibilities while preparing for the practical. A client brought up a good point "When I was first diagnosed with PD, I wanted to sign up for every available study, complete every survey – anything that might advance what we know about PD and help find a cure. Now that I've been living with the disease for many years and have learned about the research community, I'm a lot



more selective in what I participate in." Another client shared, "When I was diagnosed with Parkinson's at 51, I focused all my effort and energy on research. I ignored my mental health, my physical health, and the day-to-day aspects of life with Parkinson's. I didn't want it to be true. I wanted to find a way to make this damn disease go away. I took vitamins and bought supplements I read about on the internet. And while I believe I felt better, my Parkinson's did not go away, and I found myself getting depressed and angry. It took some time, but now 16 years later, I'm 67 and still have Parkinson's but feel I have a better balance. I participate in research when I can and read about it when something piques my interest. But now I also exercise, have conversations with my family (with help from PAA staff) about the future, and even partake in the Thinking Program PAA runs."

The future of Parkinson disease is in our hands through research. Maybe not immediately, but I think we can all agree that if we don't try it will never change, the needle will never move. We want the bright minds of today and tomorrow asking questions, seeking answers, and trying to make positive impacts in the world of Parkinson's. So, whether you read about new developments (with a critical eye), participate in a research trial, or donate; you can be proud of your efforts to move the needle! As one client put it, "Even though there is currently no cure – and may not be in my lifetime -- I have hope that gives me the motivation and realization that we need to keep moving forward with Parkinson's. And who knows, maybe the information researchers learn today will help the people with Parkinson's tomorrow."