

## THE POSTER IN THE OFFICE

The Jewish community, perhaps more than any other, is closely linked with Parkinson's. Ashkenazi Jews carry genes closely associated with the onset and progression of Parkinson's (GBA and LRRK2 amongst others). Everybody in the Jewish community knows somebody with Parkinson's. Rabbi Moshe Gruskin's father had Parkinson's, so it must have been little surprise when he himself was diagnosed with the condition.

I had the opportunity over the summer to talk to Rabbi Gruskin and get a better feel of his approach to Parkinson's and how it had come about. I had expected perhaps a rather serious man, his head full of lofty thoughts and ideas. But he was so much more than that. An infectious smile was the mark of the man who set me at ease from the moment we started talking. We talked for an hour about anything and everything and I kept having to rein him back when he asked about my attitudes and health. I found myself frequently trying to steer the conversation back to him rather than myself!

Rabbi Gruskin was diagnosed, almost casually by someone who noticed his limp, back in 2009. By his own admission he had a degree of denial and over the first several years deteriorated significantly. If you don't accept the diagnosis, it's hard to take appropriate action. Sometimes people have to take those decisions for you. And in Rabbi Gruskin's case it was his children in particular. Together they instigated and supervised an exercise program which, with the exception of the sabbath, Rabbi Gruskin adhered to. Simcha dancing! Secondly, they made sure that his diagnosis was confirmed by a movement disorder specialist rather than simply a general doctor. They asked around and one name came up each time as the best movement disorder specialist – Prof Stanley Fahn. After four years of denial by the rabbi, Prof Fahn confirmed the diagnosis formally. End of story you might think. Far from it! This was not a conclusion but a beginning and, as so often it is a tiny observation that provides the stimulus, like the grit in the shell that forms the pearl.

While in Prof Fahn's office, Rabbi Gruskin's attention was drawn to a small poster advertising an upcoming conference on Parkinson's. Hardly unexpected in a neurologist's office. But this conference was different. Unlike all other conferences on the subject, this was open to all. I don't mean all doctors. I don't mean all scientists. I don't mean all healthcare workers. I mean all. As in everybody. Whether you have Parkinson's or

whether you study, research, care for or love someone with Parkinson's. The year was 2013 and the conference in question was the 3<sup>rd</sup> World Parkinson Congress (WPC 2023) in Montréal in October.

His meeting with Stanley Fahn gave him not only clarity about his condition but a new purpose in life. His family, already a strong team, would need to be on the same page. He needed the support and understanding in decisions that needed to be made. His first decision was one which ultimately would change not only his own life but that of so many others. He could not possibly have known at that time that the connections evolving from this decision would have such long lasting impact. His decision? He was going to go to Montréal, to learn more about this condition and how to deal with it. He took his eldest son with him to help take notes. Thirty pages of notes in shorthand! He was overwhelmed by the sheer volume and depth of the information available from all sides of the community. "My brain was bursting" he said "even though we had hardly chipped away at the tip of the iceberg!"

Of course, Montréal had that effect on a lot of people "fascinating place – I got so much oomph and inspiration" he said. "My aha moment was during the WPC 2023 worship session on exercise presented by Dr. Terry Ellis of Boston University. She encouraged the need for a 'cheering squad' in order to keep on going in an exercise program! It hit me that I could do it if I had my children cheering and pushing me on"

For many it might have ended there. But not Moshe Gruskin. Knowledge is most valuable when shared. He began fundraising to send more of the community to future World Parkinson Congresses, 28 members from his community traveled to Portland for the 4<sup>th</sup> World Parkinson Congress. He plans to send 50 community members to Barcelona next year!

Rabbi Gruskin is quick to deflect praise onto others. I asked him about his inspirations for his work. "Dr. Fahn, Erika Edelman and Dr. Victor and Eli Pollard and Dr. Miyasaki were the ones who really made a difference in my decision to persevere and conquer, with God's help, the many challenges of the disease. To this day I am thankful for all the inspiration that they have given me, as it continues to propel me forward on a daily basis".

Still not enough! He wanted a plan. "We need fat" he told me with a twinkle in his eye. Before I could ask him what he meant, he explained. It was a mnemonic. F is for fight. If the condition goes so far, you need to go still further to fight it every inch of the way. A is for attitude. There is nothing that achieves more than a positive attitude and a refusal to submit. T is for therapy which must incorporate exercise. FAT – easy to remember!

Enough already? Not even close.

Rabbi Gruskin has consistently emphasized the closeness of fellow sufferers with Parkinson's, becoming a family essentially. For ages, he has offered one-to-one consultations to encourage and infuse others with his own enthusiasm. And this month sees the culmination of his Sparks of Life project providing information and emotional and financial support as always for the Jewish community but now finally from a physical building rather than having to rent space elsewhere.

I asked Moshe about his hopes for the one-stop-shop Parkinson's center that will be opening in November 2022. After a spark that happened in 2013 in Montreal, it took nine years of vision, fundraising, and work to open this building, yet it's still just a beginning for many people, "As many more people diagnosed with Parkinson's are just now coming out of the woodwork, and missing their challenges and facing the realization that they are lost and grappling with difficult issues, the center will be there for them and their caretakers to provide a feeling of camaraderie, direction and guidance". But perhaps most of all it is a "place to call home, shared with people who are in the same boat".

And you know the most amazing part of it all? It all started because of one poster in Dr. Stanley Fahn's office advertising the 3<sup>rd</sup> World Parkinson Congress. The impact of the WPC is sometimes immediate, in this case it was a long process but the results are profound.

Mazel tov!

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LifeSpark is a New Jersey, USA based organization that serves the Jewish PD community with the aim to educate and empower them to live well and feel supported. <https://www.lifesparkpd.com>