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SPEAKERS

Alfonso, Hugh, Soania, Heather, Alfonso

Heather 00:00

[Your Complex Brain theme music] This is Your Complex Brain, a podcast all about the brain, the diseases that impact it, and the path to finding cures. I'm your host, Heather Sherman, and I have the great pleasure of working alongside the team at the Krembil Brain Institute in Toronto, Canada, a leader in brain research and patient care. In each episode, we'll take you behind the scenes into our clinics and our research labs to meet the game changers of the future, and we'll empower you with the latest research to help you take charge of your own health. You'll also hear directly from patients who are living with brain disease and the care teams who support them. Join us on a journey to unravel the mystery of your complex brain. [theme music continues then fades out]

Hugh 00:59

[light, bubbly electronic music] My name is Hugh Johnston, and I've been living with Parkinson's, active and clinically, for over five years now, but the first symptoms started in the mid-'90s.

Soania 01:16

My name is Dr. Soania Mathur, and I was diagnosed with Parkinson's at the age of 28. My symptoms began as an intermittent tremor in my right pinky finger, which was really more annoying than anything else in the beginning, a little bit medically intriguing actually, considering I'd never felt what a tremor was like, but it became more constant and concerning in my right hand, and then sort of spread to my right foot, and then my left hand and my left foot. So, it became a much more prominent symptom than it started out as. [music continues]

Hugh 01:48

My symptoms started with stuff that is associated with Parkinson's like seborrheic dermatitis – that was probably the first one, like dystonia in my toes – that was fairly early on, like an anxiety disorder, which is very common in Parkinson's disease – that was maybe 18 years ago, fatigue, which is a big, big problem in Parkinson's disease. And, slowly, I would have gait disorder. I would trip. That goes all the way back to, maybe, 10 years. And eventually, after a head trauma, my toes started to shake, my foot started to shake, and then my arm started to shake, and we went from there. [sighs] [music fades out]

Soania 02:39

[light guitar music] At the time I was diagnosed, I was actually just completing my residency in family medicine. I was about to open my own clinical practice, and I was expecting my first of three daughters at that time, so not the most convenient time – [chuckles] if there can ever be a convenient time – but it was certainly a busy time of life, and at my prime. [music continues]

Hugh 03:07

I got my actual diagnosis about two years after I started shaking, and it was traumatic, and my reaction wasn't good. My doctor, I was probably one of his last patients – he retired a week after – and he basically said, "You've got Parkinson's. You got bad luck. Go away. You don't need any meds yet." And that was that. And so, I had nothing. It had quite an impact on my relationships in my family, in the beginning. It's disturbing for people to see you when you're trembling. They don't know what to make of it. [music fades out] [pensive electronic music] I went on this research journey. So, we tried to see if it was medication induced, and so, that whole conversation made people uncomfortable, but what it did do was it got me involved with advocacy. Primarily, the big difference is, I feel like I'm doing something about it, about this Parkinson's disease that I have, and it gave me a renewed sense of purpose, which I didn't really have after retiring. [music continues]

Soania 04:27

I began to slowly realize that I didn't have control over my diagnosis. I couldn't just wish it away. It was here to stay for now, but I did have a choice in how I approached the diagnosis and the challenges that it brought into my life, that it was actually not an easy choice, but my choice, to be optimistic about the future. And that's where it slowly started to change for me, and then once I stopped medical practice because of my symptoms, I turned to advocacy for patients in this community, and education and, you know, basically trying to advocate for changes to be made that will better the life of people living with this disease. [music fades out]

Hugh 05:01

[upbeat electronic music] I spend a fair amount of my time with my family. I do a bit of sailing. I spend a fair amount of time doing what my uncle said to me one day when I was frustrated, and I couldn't figure out what to do in a situation. He said, "Just go help somebody, and you'll feel better." And so, I do a fair smattering of that and, you know, I do a lot of napping. [laughs] Everything takes longer when you're retired, 'cause you actually have the time. Be with other people so that you can do things that matter through people because, on your own, there's very little you can do, yourself. It's the synergy of getting good people together who share values, share a common goal, and then it's just wonderful when you actually get there. [chuckles] It is really something else. [music continues]

Soania 06:06

When I stopped medical practice, I thought I would be bored. That was my biggest fear, that I would be bored with my life because I was so busy beforehand. Unfortunately, or fortunately, I guess, I'm probably busier now than I was, but it is, I guess, my own schedule. I spend a lot of time on writing. I spend a lot of time speaking at different events for different community support groups, or Parkinson's organizations. I sit on a number of boards. It's a disease that shadows you every second of the day,

and now shadows me during work, as well, so it's my life passion, though. It's a choice that I'm glad I made at the time that I made it. [music fades out]

Heather 06:45

[gentle electronic music] More than 100,000 Canadians are currently living with Parkinson's, a progressive brain disease that can impact mobility, cognitive function, and speech, just to name a few of the early symptoms. Learning to live with Parkinson's is a big focus of our episode today, but it's not only learning to live with the disease. It's learning to live well, with meaning and purpose in the face of challenges and uncertainty. One way our next guests are doing just that is by helping others who are on a similar journey, as members of the Patient Advisory Board at Krembil Brain Institute's world-renowned Movement Disorders Clinic, the largest clinic of its kind in Canada. The mandate of the Patient Advisory Board, or P-A-B, as it's affectionately known, is to help improve the quality of research, communication, and the overall patient experience within the clinic, and to redefine how healthcare professionals and patients communicate with each other. The hope is that this novel approach to patient partnership could help move the Parkinson's field forward and improve patient outcomes, long term. [music fades out]

Heather 07:56

[electronic music plays]] Hugh Johnston is a retired professional accountant who spent many years as a strategic advisor to several of Canada's top food-service companies, helping to streamline operations and boost efficiency. Hugh's business expertise came in very handy as the Founding Chair of the PAB. Dr. Soania Mathur is Chair of the Research Committee of the PAB, as well as Co-Chair of the Patient Council, and a member of the Executive Science Advisory Board of the Michael J. Fox Foundation for Parkinson's Research. Soania is one of the founders of PD Avengers, a global alliance of people with Parkinson's who are advocating for change, and she is the Founder of UnshakeableMD, a virtual platform helping to educate and engage those with Parkinson's to live full and productive lives. Also joining us today is Dr. Alfonso Fasano, a Neurologist and Clinician Investigator at Krembil Brain Institute, working primarily with patients living with Parkinson's. He also holds the Chair in Neuromodulation and is Co-Director of the Surgical Program for Movement Disorders. But, he says his most important job may be that of Medical Advisor to the P-A-B, a role he relishes. Thank you all for joining me today. [music continues]

Heather 07:57

Thank you for the opportunity.

Alfonso 09:14

Thank you. Thanks for having me.

Hugh 09:15

Good to be here. [music stops]

Heather 09:18

Hugh and Soania, we heard a little bit about your personal journeys in the intro to this episode, but I'd like to ask you both more about those early days, when you first received your diagnosis. Soania,

you've talked about going through a period of denial. I think that's something a lot of people can relate to. At what point did you accept the situation and decide to become an advocate for patients like yourself?

Soania 09:40

For me, it was a lot longer. I had, intellectually or medically, accepted it quite early on. I recognized that my symptoms were compatible with that diagnosis. But that true emotional acceptance came pretty much almost a decade after my diagnosis. I was sort of in that shock, anger, and denial stage for quite a long time, and I just recognized that I was becoming a very negative person, very pessimistic about my future, and that was, sort of, affecting all areas of my life, including my parenting, my relationships, and my enjoyment of life. And so, it wasn't after any one thing I read or any one conversation I had. It was after a lot of introspection that I began to understand that I really didn't have control over the diagnosis, but I could have control over the way I faced the diagnosis and the challenges that it brought.

Heather 10:24

Hugh? What about you? Did you have a similar experience?

Hugh 10:28

It's interesting. Very much so, but mine was compressed. I was diagnosed at age around, say, call it 55, and I'd actually had symptoms that showed up 20 years before, but nobody knew what they were because I wasn't shaking yet. And so, I went through those stages and, in my case, I'm a researcher by nature, and so my thing was, I reach out and try to learn. So, I guess I, intellectually, as Soania said, accepted the diagnosis quite a while before, emotionally, I was able to get there. And, yeah, it's interesting how similar it is.

Heather 11:19

Alfonso, is this quite common with patients in terms of this denial, and then acceptance?

Alfonso 11:25

Yeah, absolutely. Receiving a diagnosis of a chronic disorder has been associated to the same trauma stress that people experience after losing a relative or a spouse. It is really shocking and, basically, it's about dealing with grief, and how people deal with grief, is initially denial phase. There is an anger phase. "Why did it happen to me?" And then this acceptance. I should say that, obviously, every person is different, but there's a tendency for people with a young-onset Parkinson's disease to have a different type of processing because, unfortunately, Parkinson's disease is still seen as the disease of the elderly, and that's not true. And so, there's more anger. There's more denial. There's also the tendency to mask the symptoms, so people don't want family members or co-workers to know, because this happens in the middle of their career, as you just heard, and again, since people don't know what really Parkinson's means, automatically, when you say Parkinson's, you think about a shaky old man on a wheelchair, and that's not Parkinson's. So, for the stigma, people tend to stress more about masking the problem, and covering it, more than dealing with the problem itself. So, as a doctor, part of my job is to guide them through this process, and to let them see that there's nothing to be ashamed of, to teach them about what's available, what's not possible to be achieved with current knowledge, but there are a

lot of resources, a lot of things that can be done. And certainly, one of them is acceptance and, obviously, not everybody's dealing with this the same way, and this is where dealing with a psychologist sometimes, or with a good friend, or a good family member, or even your doctor may make the difference.

Heather 13:16

[gentle electronic music] Absolutely. Well, we're all here today because of your involvement with the Patient Advisory Board. So Soania, I'll start with you. What makes this Board so special and unique in terms of patient advocacy?

Soania 13:29

Well, I think we need to sort of discuss a little bit about why patient advocacy is so important in the clinical and research field. I think the patient voice needs to be incorporated into these areas because we're no longer in that paternalistic type of relationship with these communities. There was a time when what the doctor said -- when the patient's job was just to follow the suggestions that were made. We're now at a time where things are much more patient-centric, both in terms of medical management, as well as the direction of research and involving patients in the research voice. So, this board is really a reflection of that, in terms of the experience that patients have when they come to the Toronto Western Movement Disorders Clinic. And it's unlike a lot of boards where it's been more tokenistic involvement. This Board is really just to have a powerful voice in terms of influencing changes, both in the medical clinic as well as the research direction of the research being done there.

Heather 14:25

Interesting. Hugh, would you agree?

Hugh 14:28

Yeah, I would very much so. And there is a secret sauce to that. This faculty group -- I've been on a number of these, as Soania has, as well, and Soania has got way more experience than I do, and I see the exact same things. This group of clinicians and staff is different. They actually want to know what the patients and the care partners think and feel, and not only that, they actually want to do something with it. There are lots of patient advisory boards out, that the people from the staff and the clinicians are wonderful. They just have no idea how to actually action any of the information they're getting. And this group, I say it this way: they often don't ask a question unless they plan to do something with the answer.

Heather 15:23

Alfonso, what are your thoughts? You're the Medical Adviser of the P-A-B. So, what's your role, exactly?

Dr Fasano 15:28

My role is to learn, and somewhat to steer the conversation towards more scientific components. I'm not saying that the scientific part is the most important one, but it's part of the discussion. I guess my role is also to let them know what, idealistically, is difficult to be achieved, and what's more concrete and possible because, sometimes, you know, people have an idea about healthcare. "What can be

done?" And you know, "Why don't you do it this way?" Yeah. Well, for example, "Why don't you have a walk-in clinic for patients with chronic neurological disorders?" That would be, actually, my ideal setup, but a walk-in clinic requires a certain arrangement, and manpower that we don't have. So certain things are perfect on paper, but that is difficult to implement. So, part of my role is to tell them what can actually be done, but also be inspired by them.

Heather 16:19

Well, why does advocacy and collaboration between the medical community and patients matter so much? What are some of the tangible benefits that can come out of it? Soania?

Soania 16:29

Well, advocacy, or collaboration between these different communities, can really change the life experience for patients. As I mentioned before, the collaboration with your medical team allows you to build a care team that's dedicated to your optimizing quality of life. Because we don't have a cure for Parkinson's disease, it's all about quality of life, and assembling a team of, you know, your physicians, as well as allied health professionals, can really help you optimize your life experience. In terms of collaboration with the research community, I think that's really something that is fairly new or recent, not accepted by all research, but researchers like Alfonso are definitely an example of that acceptance. And it helps in a number of ways. First of all, it's just an ethical thing. I mean, how can you dedicate your work's life without knowing what the community is like? How can the most-impacted stakeholders in this whole equation not be part of the equation? So, I think that's one reason that it's important for that collaboration to occur. I think it's also important for collaboration to occur because only patients know what their life experience is, and we can't assume that researchers know all those subtle nuances that this disease can take. So, the direction of research, looking at what is grounded in relevant clinical need, is really important. Designing the studies is really important. Studies have shown that patient retention and patient recruitment are definitely improved when you have a patient involved in the research process or developing a research study. So, things like that, I think, are really tangible, positive outcomes when you have collaboration between these different communities.

Alfonso 18:05

I just want to say, very quickly, two things. The first one is that I don't see clinical neurology without research. I mean, it doesn't mean that any neurologist has to be a researcher but, at the end of the day, any good neurologist has a research mindset, has the mindset of a researcher, because we don't have the answers. Most of the time, we are very ignorant about these conditions. The second thing is that I strongly believe that patients and their needs are the starting and ending point of research. Very often, we see people that are talking about looking at specific things, and they're publishing very successfully, but the immediate impact of what they're doing is not necessarily clear. It might be clear one day, and I'm not questioning that, but I think patients want answers to very practical questions like, you know, "Why am I constipated?" "Can you do something about my pain?" "Can I move better?" "Can I stop falling?" These are the main problems that they have. The problems of Parkinson's disease is not tremor. This is what people think, but it's not. And, unless you talk to patients and see what they want to achieve, you don't know that, and you focus on something that is not relevant. Yes, you still publish, you still go to conference, you're still successful and well-known as a doctor, but it might not be so impactful as we think it is.

Soania 19:20

[gentle electronic music] I think that's a really good point, Alfonso. I think that the drive to be scientifically relevant is not the same as clinically relevant, and I think that makes a lot of sense.

Hugh 19:28

Yeah. There's a diversity that comes with engaging with patients, because they bring talents and skills that the clinical and research teams actually don't have. And, if you engage with the patients, you'll discover what actually matters. And I'm going to quote an old business guru who's gone and just to be a business guy, but Peter Drucker once said, "There are no results for marketing. There are no results for operations. There's no results for anything, other than results for the whole, and for the organization," and you could say that there is no such thing unless there's results for the patients. "Do they function better? Is their life better?" It's not just a series of symptoms, and this and that. And you get more of that when you actually go and, you know, you see all the people, all the time. But, as Alfonso said, if you're not a clinician, you're not seeing very many people who've got Parkinson's disease, which means your opportunities to learn something are very limited. [music continues then fades out]

Heather 20:37

Well, let's talk about why there's such a need for this type of partnership. The World Health Organization has declared Parkinson's disease as the world's fastest-growing neurological condition. So why haven't there been new approaches? Why has it been so long since there have been new therapeutics and new treatments for patients?

Alfonso 20:54

I think the first step is awareness, awareness of a particular thing. Parkinson's disease, even though we call it disease, is not a single entity. It's not a disease. We should either call them Parkinson's diseases, or Parkinson's syndrome. We now came to the conclusion that we're dealing with a syndrome caused by many different etiologies, many different causes. Some are genetics, some are environmental, and some are the combination of genetic background and predisposition, plus what happened to you in life. I should also say that, over the years, even though we say there's no cure, there's been an explosion of new symptomatic therapies. Maybe there is nothing new for the past five years, but new drugs are coming and, you know, we're getting better at treating Parkinson's. We are not close to stopping the progression, but I still remember, I've been seeing Parkinson's patients ever since I was a medical student, and I don't see any more the problems that I happened to see when I was much younger. And this is indicating that these symptomatic therapy are doing a better job. And finally, I want to say that even though we're not curing the disease, because of symptomatic therapy, Parkinson's patients are living longer. Actually, they live almost as long as people without it. In the past, before levodopa was invented and discovered, people with Parkinson's will die in nine years, on average, obviously. Now, they live for many years. A different story is their quality of life, but there are, you know, brain operations that can help them during the course of the disease. And even those, even as I said, these therapies are not cures, they are still quite effective in changing the natural progression of the disease. [gentle electronic music] Because of these therapies, people can now exercise more, can be more

active, they can have more engagement, they can still keep their job, and this creates a win-win, whereby they can help themselves more.

Soania 22:43

I truly respect Alfonso's thoughts on how things have gone. The unfortunate thing is that, in the patient community, there's still this view that we're still dealing with the gold-standard drug that was developed, you know, over 50 years ago, and that's what we're comparing all current treatments to, which is fairly frustrating, I think, for the community at large. I think we can't cure what we don't know, and I think the knowledge base still has to expand because the brain is the most complex thing in the universe and, to understand [chuckles lightly] what's going on in the brain for everybody who is affected by these Parkinson types of disorders, is going to take some time. Definitely, quality of life is important, so we're not just looking at duration of life, but quality of life. And that has, I think, improved, as Alfonso said, with the symptomatic treatments that we have, and the ability, now, to function, I think, a little bit better. But we're still really pressed for time, and those of us that are impacted by this disease don't really have a lot of time. [music continues]

Alfonso 23:45

And, in this regard, I entirely agree with you. And I'm not saying that I hope we're going to be using levodopa for the rest of our lives. But it is what we have, and it has done, you know, a lot of good for many, many people. It's not enough. I agree with you. [music fades out]

Hugh 24:01

It's interesting. Yes, patients are frustrated. They don't really have time to wait for the cure for the next generation, and the wonderful thing about Toronto Western Hospital is, is we're actually working on therapies that are going to work right now. Alfonso's whole team works on things that have impact on people's lives right now. Not only do they help people to have better quality of life. In some cases, they save their life. It's an amazing thing. And, on the other side of the spectrum, there are therapies, physical therapies, mental therapies, there are all sorts of things that Toronto Western is working on, as well, from the mind side. We even have a neuropsychologist on staff who is doing groundbreaking work with a certain group of patients, where there's an opportunity to really improve their symptoms and their quality of life. And so, we have a unique group of doctors here, and there's a reason why we've got a whole bunch of them in the list of the top 50, 100 Parkinson's researchers and clinicians in the world. And we're very, very lucky to have that here.

Heather 25:29

Isn't this just the beauty of having patients so engaged at this level, is that Hugh knows everything that's going on in research at the Institute right now?

Alfonso 25:37

Yes. It gets stressful sometimes. You gotta go home and study before you meet them, because they're going to know more than you, and that's actually motivating you to do a better job. It's something I always say. It's not a one-way street. It's not that the doctor has to deliver. That's it. I don't like patients who don't do their part. I need them to exercise. I need them to be informed about the disease. I need them to challenge the doctors. It's true, we don't want the paternalistic medicine, but this also means

that patients need to be an active part of the team, and that's something I strongly believe in, and it's been part of my approach to this job ever since I can remember. Because this idea of the doctor knowing everything is actually wrong. Doctors can learn, can make mistakes, but it's a mutual and respectful relationship where, you know, we're trying to do our part, and we're alike here. We are part of one team.

Soania 26:29

I couldn't agree more. I mean, because there's no cure for Parkinson's disease, it is all about quality of life. And only patients know what their quality of life goals are, and how they can achieve those goals. So, I often tell fellow patients that you can't be a passive observer and expect to live well with this disease. You have to be an active participant. You have to assemble your team. You have to do extreme self-care, including exercise and diet, and sleep, and stress reduction. [upbeat electronic music] You have to, basically, take control over those variables that you do have control over in order to make for a successful management of your disease.

Heather 27:02

Mm, okay. Soania, I'm just curious, what changes, or what kind of impact have you witnessed in your time as a member of the Board, and also just in general, in patient advocacy?

Soania 27:12

I think that the patient voice is becoming more embedded in the work of the clinical and research communities. I think that the importance of patients being a part of those decisions that are being made for their health care, I think that is becoming more valuable and respected. And then, you know, the world of Parkinson's really has changed over the last 24 years. The direction of research has changed. You know, when I was first diagnosed, it was all about dopamine replacement. And, as Alfonso mentioned, there are many other treatment modalities that have come out since that time where it's not just all about dopamine replacement. We're looking at, sort of, more shots on goal. So, it's changed substantially since I was first diagnosed all that time ago. [music continues]

Hugh 27:54

There's an interesting thing. You have a diagram that you see a lot in Parkinson's. It's an iceberg, and it has the motor symptoms and the big five or four, whatever you want to call them, and then, on the bottom of this iceberg, there's these things we call non-motor symptoms and, in a way, it's almost like they would be described as things that, kind of, come along as excess junk, [music fades out] but they are actually symptoms of the various types of Parkinson's disease, and not everybody gets the same bunch of them, because they have different kinds of diseases. And one of the things that I think is coming, partially from that connection between the clinicians and researchers, and the patients, is this understanding that the anxiety disorder is linked to the freezing of gait motor disorder, that the apathy that comes with Parkinson's is related very much to all the circuitry, and the same types of chemicals in the brain that are involved in the movement. You know, dopamine is used for a number of systems in the brain, and the brain is extremely complex. And as Soania said, it was all about one thing, dopamine replacement for movement, they're seeing the human as a complex, multi-factor system that you just can't push one button and it's going to get better. What do you think, Soania?

29:33

Yeah, I couldn't agree more, Hugh. I think that, you know, there was a time where, as a physician, if I gave a patient that had a tremor, medication that reduced the tremor, I would consider it a success. But now, we kind of look at it and say, "Is that really successful if the medication I've given that patient gives them side effects that are worse than the tremor initially was? By not addressing their constipation? Or their social anxiety? Have I really improved their quality of life?" [gentle electronic music] So I mean, I think that look of the patient as a whole, how this disease affects us, you know, emotionally, mentally, socially, spiritually, as well as physically, I think is really, really important.

Hugh 30:09

There's one other thing that Alfonso mentioned that he invited me, very generously, into the clinic one day, and the patients that I met that day changed my life forever. Their quiet bravery in the face of some of the most aggressive types of Parkinson's disease that we could come across, which many of Alfonso's patients are like that. They have very complex cases. To me, it's important that we all have better quality of life, but it's also important to recognize and realize there are some people who have Parkinson's, who this is just a train wreck in their life, and we need to do more for them. We need to remember that it's not just all about us, that there's some people out there who are really suffering.

Alfonso 31:13

Yes, and actually, this is an important point that I think we should emphasize, that with the Patient Advisory Board, it's not just about doctors-to-patients communication, but also patient-to-patient. [music fades out] This patient-to-patient exchange can be beneficial in many, many respects, and I can think of two in particular which we're working on right now, actually. One is to create support groups. Ideally, we should have a support group for early-onset Parkinson's disease, because it's a different entity. We should have a support group for people who went for deep brain stimulation, because sometimes things don't do as well as they were initially, or as well as they're imagined, and there's a lot of need to share their experience, their frustration, their little successes, and this helps. The other component to this is educating because, you know, I can tell a patient about deep brain stimulation, which is what I do mainly, for hours, but it will be way different for a patient to hear from another patient how the experience was, how it is to be in the operating room. This is where, you know, talking to another person who went through the same, with the same fears, because we are all humans in the end. We all have the same questions, the same fears. We may have different needs, different values to some extent but, deep down, we always have the same questions, and this is where sharing with other patients – not necessarily with doctors – can help.

Heather 32:36

That's amazing. It's sort of a nice lead-in, too, to my next question, which was about PD Avengers. That's the organization that you co-founded, Soania, and I know Hugh is a member, as well. Can you tell me about it? What's the mandate?

Soania 32:49

Sure. Thank you for asking. The PD Avengers was -- we founded it almost two years ago – it'll be two years this summer – and it's basically, we're a global advocacy group that's interested in providing a unified voice for the Parkinson's community across the world. And we have three pillars that we

concentrate on: wellness, advocacy, and research. And it's about connecting different organizations so that we work as a group. That collaboration is really key, so spreading the messages of our partner organizations. We have over 100 partner organizations at the moment. We have more than 5,100 members of the PD Avengers across over 90 countries, I think now, and the needs of our community here in North America, for instance, are very different than the needs of the community in Uganda, or in Japan, or in India. So, trying to find ways that we can, sort of, have a unified voice, and work together towards ending this disease, is really what the PD Avengers is all about.

Hugh 33:50

The thing about the PD Avengers is that they are focused on bringing people together to learn from each other. There's this thing that happens to organizations that are out there to help people. They end up being all alone in a dark space. We need to put them together so that they can get the benefit of, you know, this one has awesome marketing, and this one has great research capability, and they all have different strengths. And, when you put them together, and you focus on what matters to the patients, then you go with one voice, and it's easier for governments and funders to then sort out, "Okay, I get what these people are now. They're all talking from the same songbook," as opposed to, "Gee, look, there's a bunch of cats out there. Boy, there's a lot of cats. I don't even think I have time to talk to all the cats." And so, it's important work.

Heather 34:55

[gentle music] Soania, I wanted to ask you, you have this amazing video on your website, UnshakeableMD. It's called 'Dear PD' and it's sort of a message to this disease that you've been living with, almost a warning. And I just wondered, you know, where does this come from within you, this fight?

Soania 35:12

Hmm. That's a great question. It comes out of the fact that it can't be any other way. I mean, I have this diagnosis, and it's up to me to decide how I'm going to face it. I can face it with fear and trepidation, as I did initially, in my journey with this disease, or I can face it head on and take those challenges on and try and live the best life I can with this disease, as we look for that ultimate cure, and inspire others to do the same because it's all about quality of life, again, know that that's what we have to work with. And that fight, basically was more of a reflection on the viciousness of this disease, but how we, as patients, need to sort of stand up to that viciousness, and try and fight against the disease that we may not have control over, but certainly can face it differently. And I think also, the fact that I have three daughters, I mean, there was no choice but to move forward, and to move forward with this disease in as graceful a way as possible because, you know, it had the possibility of really affecting them in a negative way, and that's the last thing I wanted to have happen to them. So, I think by facing it in the way that I faced it, and am facing it, has taught them instead empathy and compassion and charity, and it's taught them that life isn't going to be perfect, but how you face that imperfection is going to determine how you are as a human being.

Heather 36:37

Absolutely. Hugh, I've known you and worked with you for a few years now, and I have to say, I'm consistently blown away by your optimism and your determination. So same question to you. Where does it come from, that fight? And can anybody tap into it?

Hugh 36:53

Well, it's interesting. Go meet an advocate. It's, like, infectious. Like, I went to this conference that I got invited to, and I met Alfonso there, and I'd met him before, but I met all sorts of clinicians, and I sat beside Soania and Ben. You know, I've had my times when I've been negative and down, and it happens to all of us. As my 88-year-old mother-in-law said, "Hugh, everybody has problems. It's not just you." And I've seen people with great disability have joyful, happy lives, and I've seen people with minor ailments be very unhappy and have poor quality of life. And so, you get to choose, but it isn't easy. It's not just like some wonderful, you know, "Here we are. It's TED Talk. It's your guru of the decade telling you, 'It's all wonderful. Just turn on your happy bulb.'" No. It's making a choice every day to get up and take the wins, take the good days, and push through the hard ones and the bad ones, because there will be a lot of those.

Heather 38:15

Alfonso, what do you get out of this, personally and professionally, this connection with patients on this level?

Alfonso 38:21

Oh, it's fulfilling, to say the least. As Dr. Lang, the Director of the Movement Disorders Centre once said, "It's been the most fulfilling project we've been working on in the past five years," and probably even more. To me, it's really an opportunity to learn. As I said at the beginning of this conversation, to see what they think, to see where they're wrong, and, more importantly, where we are wrong, the medical community. I often discuss medical topics, even with patients that I would have never met in my life, on social media, like on Twitter, and I realize more and more that there's a lot of anger out there towards doctors, and this is because we're not good at communicating. We're not good at communicating the complexity of the diseases. And talking to patients, talking to the P-A-B, learning from them, it's given me the strength and also the tools to do a better job as an educator, with my fellows, other doctors, and more importantly, as a doctor, and also as a person who tries to engage with other people out there to spread the word that doctors are on your side, basically. We're trying our best and we're humans. We make mistakes. We can't always be there and, you know, I've made a lot of mistakes in my life, and I'm not ashamed of it. I'm just trying to do better, day by day, learning from my mistakes like everybody should do and, in that regard, being with patients all day long, and talking to them all day long, is a mirror, the mirror they you need to see whether you're doing the right thing or not. [upbeat electronic music]

Soania 39:47

That's great. Well, Hugh and Soania, if somebody wants to become a patient advisor or an advocate, what are some of the steps that they can take? What kind of opportunities are out there? What's the take-away message for somebody listening right now who wants to get involved?

Soania 40:01

I mean, for me, advocacy's all about empowerment. It's empowerment for yourself, in terms of being in control of your life experience, and your medical treatment, to optimize your quality of life, and also empowerment for directing research and giving those in your community, that actually may be voiceless, and don't have the opportunity to influence change in the way that this disease is seen and treated. So that, for me, that's my driving force behind what I do. For others, it may be a special interest. Somebody may have a special interest in supporting other people with their disease, or that share the similar life experiences, and they can focus on that in terms of getting involved in support groups, etc. Some others may be involved with research, and in improving enrollment in research. So, look for where your strengths are, and what your interest is, and there's plenty of opportunity for all of us to become advocates. [music continues]

Hugh 40:51

Pick up the phone, send an email. I sent an email. Soania and Ben Stecher, and Sara Rigarre, and John Stamford were just inspirations to me. So, I sent an email to Sara Rigarre in Sweden, and she answered me back. And I sent an email to Ben Stecher in Toronto, and he said, "Want to have coffee?" and it went from there. Dip your toe in and try something. "Oops, that's not for me." That's okay. Go dip your toe in somewhere else. And you don't have to say, "Oh, I'm so sorry. I don't think what you do is very good." No, no, no, it's great what you do. It's just not what I'm good at. I'm going to go over here and try this, just keep dipping that toe in until you find something that just makes you sing -- I don't know about you, Soania, but you've had a second career doing this, and you're a world leader, and for me, it's just given me a sense of meaning again in my life after retiring and having really nothing that was vocationally meaningful for me. And so, yeah. Go for it. And, if it doesn't work first the time, go again.

Soania 42:05

Absolutely. I think, you know, when I stopped my clinical practice, I spent about two years in mourning because I enjoyed family medicine so much, and my patients so much. But now I look back and I say, "You know, everything happens for a reason," and this was really my true life purpose, to help support this community in any way that I can. And so, yes, it has given my life meaning and I feel like I'm following my passion.

Hugh 42:28

You're very, very good at it, Soania. And Alfonso, you're very, very good at what you do. And it's interesting. Alfonso reminds me of one of my CEOs because Alfonso's a perpetual learner, and even when he doesn't like the answer, eventually, it sits in there and stews away, and he puts it to work. It's good stuff. I gotta tell you, a lot of people just get stuck in what they're doing. It's easy to do that, because life is hard for everyone. And so, being open minded is a hard thing to do and, like I said, Soania, you and a number of the advocates are just absolute inspirations. So, for people, jump in, and you won't believe who you're going to meet.

Heather 43:19

[gentle electronic music] Well, this has been an amazing discussion. I just wish you all the best. I'm so glad that you joined me today.

Hugh 43:25

Thanks, Heather.

Alfonso 43:26

Thank you.

Soania 43:26

Thank you, Heather. [music continues]

Hugh 43:32

So, my message to people who have just gotten a Parkinson's diagnosis and are wondering about, "What does this mean for me? Am I going to die young? What's going to happen to my family? Is this going to affect my work, if I'm still working?" And the answer is, "You're not going to know until it comes, and it will affect you, often, as much as you let it affect you. A disability is a disability. It's not your life. You can lead a very, very full life if you choose to do that." [music continues]

Soania 44:13

If there's anyone out there right now, listening, that has had their life touched by Parkinson's, be you a patient, or a care partner, or have a loved one with this disease, know that you're not on this journey alone. There's a huge and very supportive community available to support you through this. Also know that you have to be an active participant in order to live well with this disease. You can't be a passive bystander. You have to take control over those variables that you do have control over, like your self-care routine, your sleep, your nutrition, your stress level, and you have to assemble a supportive healthcare team, made up of allied health care professionals, your physician, other supportive individuals that have your best quality of life at heart, and understand that you may not have a choice in terms of the diagnosis, but you do have a choice in terms of how you face the challenges that this disease brings. [music fades out]

Heather 45:07

[Your Complex Brain theme music] Thank you to Dr. Alfonso Fasano, Dr. Soania Mathur, and Hugh Johnston for joining us on the podcast today. If you'd like to hear more about Hugh and Soania's stories, or their journeys with Parkinson's, head to our website at uhn.ca/krembil and click on the show notes for today's episode. This episode of Your Complex Brain was produced by Jessica Schmidt. Executive Producers are Carley McPherson and Tobin Dalrymple, with production assistance from Dr. Amy Ma, Twayne Pereira, Sara Yuan, and Suzanne Wice. If you enjoyed what you heard, please tell your family and friends, and leave us a rating and review on your favourite podcast listening app. Thanks for listening. We'll be back in two weeks with another exciting episode. Have a great day. [theme music fades out]