



The YOPD Council
Traveling with Parkinson's
March 2022
Davis Phinney Foundation

Polly Dawkins (Executive Director, Davis Phinney Foundation):

So, without further ado, I would love to introduce my panelists. May I go around the room and just point on you and have you say hello and perhaps where you are today and why is the topic of travel interesting to you? So, I'm gonna start with Kevin because you're in my upper screen. Kevin, please introduce yourself.

Kevin Kwok (Board of Directors member, YOPD Council Leader, Davis Phinney Foundation):

Good afternoon, everyone. I'm Kevin Kwok, I'm a board member with the Davis Phinney Foundation, and I consider myself to be a road warrior with 3 million miles of actual traveled miles. I have a lifetime plan, a membership with 2 million on United and 1 million on American, which means that that's way too much travel. But travel, I would say about a third of those miles happened after my diagnosis because of work.

Polly Dawkins:

Got it. Thank you, Kevin. You'll have a lot to add to today's conversation. Karen, welcome.

Karen Frank (Ambassador, YOPD Council Leader, YOPD Women's Council Leader, Davis Phinney Foundation):

Hi. Well, how do I follow that with the travel Kev? Yeah, no, I just got back from Colorado actually. And so, all my suitcases are still in the back of my car because I'm relaxing. So, my name's Karen Frank, I live in St. Louis, Missouri. And I really did just get back from two months in Colorado. So, I'll talk about that later. So welcome today, everybody. And I agree with Carl Robb, who commented and said, can we leave PD at home?

Polly Dawkins:

Right.

Karen Frank:

That would be wonderful. That would be great.

Polly Dawkins:

Kat. Welcome.

Kat Hill (Ambassador, YOPD Council Leader, YOPD Women's Council Leader, Davis Phinney Foundation):



Thank you. Hi everybody. I'm in Portland, Oregon today, and I am aspiring to be Kevin. I have been an avid camper and outside enthusiast with my family and my husband. We are, I have not done a ton of travel until I got Parkinson's because I retired from a busy practice that kept me pretty close to the hospital. So, I am learning to travel. We are selling our family home. Actually, we just sold our family home and are buying an Airstream trailer and planning on traveling a lot. We own a small trailer now, so I do have some tidbits to share. So, thanks for tuning in today.

Polly Dawkins:

Wonderful. Thank you, Kat, Tom.

Tom Palizzi (Ambassador, YOPD Council Leader, Davis Phinney Foundation):

Good afternoon, I guess everybody, it's afternoon where I am in Denver, Colorado. I've been on the YOPD Council for a little while here, but we do a lot of traveling. My wife and I have traveled for years and we traveled when our kids were here and now that our kids are gone, we travel as much, if not more. I just got back from Palm Springs after a week there. So, you know, traveling's fresh on my mind as well, my bag is unpacked by the way, Karen, but anyway, that's just cause I got home last night, but here to answer your questions.

Polly Dawkins:

Super. Hi Heather.

Heather Kennedy (YOPD Council Leader, YOPD Women's Council Leader, Davis Phinney Foundation):

Hi, I'm Heather, I like long walks on the beach. I have TSA pre, no, wait, I have TSA clear. Call me. And I have a roller bag that goes four ways like my hips used to do before Parkinson's.

Polly Dawkins:

That's terrific. Sree. I'm sorry. You have to follow that.

Sree Sripathy (Ambassador, YOPD Council Leader, Davis Phinney Foundation):

I know following Heather is always a tough job, but I have my Davis Phinney shirt on to give me extra power. Woo. So, my name is Sree. I'm a Davis Phinney Ambassador and part of the YOPD council. And I am from the San Francisco bay area. My first experience traveling is surprisingly from my mother's womb into the world. I consider that an elite travel experience. But more recently I've been traveling throughout the United States. I've been traveling for the last three months, and I just got back home and I'm about to hit the road again in a couple of days. And I've actually traveled more with Parkinson's than I have in my life. In fact, in 2019, I did a round the world trip, visiting New Zealand, Australia, most of Southeast Asia, many countries in Asia and Japan, and learned a lot about travel. I wasn't as progressed back then. So, I'm learning a lot about how to deal with Parkinson's and travel from my recent experiences. So happy to share.

Polly Dawkins:

Super. What we thought we'd do today is maybe start with some things that you've learned, traveling with Parkinson's tips, tricks, hacks, and perhaps answer some questions immediately from folks and then maybe dive into is traveling right anymore with Parkinson's? How have you adjusted your travel? So, let's start off with, Heather, you started with your suitcase that goes four ways.

Heather Kennedy:

Pretty neat.

Polly Dawkins:

Can you talk a little bit about that? And why have you?

Heather Kennedy:

Highly recommend for those of us who are challenged with motor symptom disorders. You can wheel the bag every way instead of just dragging it or pushing it along in a straight line. This came in handy in Japan, where there were textured sidewalks for the blind to follow. We had to literally carry the suitcases that didn't have those wheels that go every way. And it's just helpful because you have to be able to pivot as Kevin Kwok said in his Davis Phinney speech, pivoting is important. So, there's that, and there are some other things too, that we can do to prepare for travel. Like I said, TSA pre gets you through there without having to take those shoes off in case you're gonna light the plane on fire with your shoes, the TSA, you know, gets you through a little quicker, or you could do CLEAR, which does cost some money. If you can afford it, it gets you through a lot faster. In fact, I think that I've seen people walk straight to the front of the line. I'm like, hey, they're budging. And after we blacken each other's eyes, I realized that I was in the wrong and it turns out I don't look so good in orange either, just saying, but I won't fight in the airport anymore. I promise.

Kevin Kwok:

CLEAR is a wonderful thing. I highly encourage people who travel by plane frequently to think about investing. It just puts you at the front of the line. And I tell you every time I take off my shoes or my belt, sometimes I want to cry trying to struggle to get it back on. Just being able to cruise through is so nice.

Heather Kennedy:

Yeah.

Polly Dawkins:

And is that membership a yearlong membership?

Kevin Kwok:

It is.

Polly Dawkins:

And do you all find that's better, CLEAR than TSA precheck?

Kevin Kwok:

Well, you could do both.

Heather Kennedy:

Yeah. Why not double up?

Kevin Kwok:

By doing both it actually cuts a lot of time out.

Polly Dawkins:

And stress probably.

Kevin Kwok:

Well, that's actually, that's the biggest thing with travel is doing the little tricks of developing routines, making sure that you pack the same stuff that you need, your medications are in the right place. And even knowing what pockets to put things, right?

Like I wear certain blazers where I put my phone, my passport, my wallet, the meds, you gotta know exactly where you wanna put your meds and don't keep 'em just in your check bag. But having a checklist really makes, takes the stress away from travel.

Polly Dawkins:

A travel checklist.

Tom Palizzi:

Yeah, I totally agree with that. I keep a, I have this thing that I call the ultimate packing guide and it just, you know, everything from the hairbrush to, you know, whatever else I can possibly think of. And then I have to go through that checklist cause I just can't, I can't remember what it is I packed and haven't packed. So, it helps a lot. And I'll pack about, I start about three days before I leave and when I was working back before Parkinson's I'd pack in like a half an hour. So, and then I think to that end leave early as well for the airport. So, we all, we used to leave about two hours before our flight, or least three. Of course, it takes a while to get to the airport about half an hour, 45 minutes or so. But having that extra hour cushion for me takes away some of the stress and I can function better. So.

Kevin Kwok:

I don't know how the rest of you on this panel feel, but I don't like checking bags because I use my roller bag to actually haul my briefcase and all my other things on top. And whenever I go

international and they say, well, you're over the weight limits. You gotta check it. Invariably, I end up losing a bag or something. But, having enough time to store your bag is everything.

Kat Hill:

Yeah, I wanted to reinforce that, that for me, I need extra time for all of it. I take more time to pack. I make more lists because running late or feeling pressured at all will really escalate my symptoms. So, I don't wanna be cutting anything tight. I follow a routine, like a lot of folks mentioned with a packing list and that includes, you know, doing a lot of driving travel too. I don't, I like to set a loose guideline about when we're gonna arrive somewhere so that I feel like I have wiggle room if I need to stop more or stay stopped longer. Because that's what will really activate my symptoms a lot.

Tom Palizzi:

Yeah. I go so far as I have a handicap placard that I carry in each of the cars. And then I'll also ask for early boarding on flights, cause that helps a lot when I can get myself out of the way, I'm much less inclined to panic along the way or freeze or something like that, which has happened. But then you can just take the parking placard with you when you're traveling, wherever it is you are. The other thing that's really good to do when you're at an airport, especially an unfamiliar airport, is ask for a wheelchair assistance. Cause I mean, I can't tell you how many times we've gotten into trouble just trying to find where we're supposed to be. You know, we're arguing over where we're going and trying to figure that out. Whereas if you're in a wheelchair, they know right where to take you. And again, it can avoid a lot of problems and avoid a lot of delays.

Polly Dawkins:

Interesting. Kevin?

Kevin Kwok:

I wanna show you my favorite travel tool.

Tom Palizzi:

Is that your custom...

Karen Frank:

A collapsible cane?

Kevin Kwok:

Yes.

Heather Kennedy:

Pool cue... Weapon.

Kevin Kwok:

This gets you on planes all the time, easy. People wanna help you with your bags. And it's wonderful when you're OFF and my girlfriend bought it for me for hiking, but I don't travel without it anymore. It really helps a lot. And it's amazing how people part ways when you come up with your walking stick.

Heather Kennedy:

The chat is great. Can you fish with that, Kevin?

Tom Palizzi:

Yeah that is good.

Karen Frank:

It's a waiting staff, doubles as a waiting staff for fishing.

Tom Palizzi:

Yeah. Kevin, that's a good cane because it breaks down to be so small. I have a cane that I traveled with a couple times and it was just such a pain in the butt cause it was too hard to store...

Kevin Kwok:

Right.

Tom Palizzi:

I'm into that custom three-piece pool cue you go out there, think that'll work out good.

Kat Hill:

And a lot of the walking sticks, even if they don't aren't bendable, they telescope really well into smaller pieces cause that's, I found that same thing, Tom, that, and at first I was really proud about it. Like I wanna do it by myself. I wanna do all the things. Karen and I heard you say that earlier. I wanna take care of it all myself. I don't wanna ask for help. And that's a hard thing to do, but I've learned that if I can be gracious in accepting help or asking for help, my energy's better throughout the whole experience because part of it is, as we all know, is pacing ourselves. So, it's sometimes humbling. We don't always wanna say, hey, we're the disabled ones. Yes, we need more time to board, but it really can make an impact in your overall experience. It's not just in the moment.

Karen Frank:

The one thing.

Kevin Kwok:

I'm gonna be a little controversial and ask question, is travel good for us?

Tom Palizzi:

I think...

Karen Frank:

You know, I don't, I'm not so sure. My father used to get so stressed out about travel and they used to love travel and as his Parkinson's got harder for him, he didn't enjoy it anymore. And it added to his stress, and it maximized his symptoms. And there was a point at which he no longer wanted to do it because it was more pain than it was joy for him. I believe there was that tipping point. But I think the routine also, I find that it difficult to switch my routine when I'm going places. I don't know that travel is bad for us cause I do wanna continue to travel, but I think it does affect us differently.

Kevin Kwok:

Yeah.

Karen Frank:

And I think you have to make room for that in your plans as you're traveling. I don't like to have like solid times to something like we had to buy tickets to go to the Anne Frank House. And that was really, really hard to get through Amsterdam, to find this place on rough sidewalks at a particular time. And I don't wanna miss out having to go, but you know, you can call them and tell them you have a disability and it's hard for you to get there at a certain time. And is there a way that you could enter when you get there, and they will usually make accommodations and another experience I had most recently in Colorado cause I was there for eight weeks is I really wanted to go to the Colorado athletic club and I went there, they don't have short term memberships. So, I just started talking with them and I told them I was in town and I was working with the Davis Phinney Foundation and that I had Parkinson's and they were so nice. They actually gave me a free membership for five weeks to their facility. They said, let's give you a week pass. We'll get back to you. And a week later I got an email and said, enjoy your time here. And it was just about sharing with somebody and telling them about my Parkinson's and it turned out that someone else's family member had had Parkinson's and it was just a learning opportunity. It was great. It was really nice.

Tom Palizzi:

Which CAC, were you at, Karen? The one in Boulder?

Karen Frank:

The one in Boulder, yeah.

Tom Palizzi:

Well, we used, they used to host a pedaling for Parkinson's class for us for free and they provided everything. They were really great people to work with for a private health club.

Karen Frank:



That's really kind, that's great.

Tom Palizzi:

Especially an upper end health club to do something like that was I thought pretty cool.

Kevin Kwok:

I like this comment that Becca says on here about building flexibility, the flexibility muscle, because you constantly have to shift and adjust and pivot when you're traveling. And I think Becca brings it up, it's really useful and good for us, but at the same time, I'm more drained than ever after a trip nowadays.

Polly Dawkins:

So, are you traveling less Kevin than you... you've got your 2 million mile membership.

Kevin Kwok:

You would think that I would always be constantly on the road on frequent flyer miles. I actually am becoming a little more, not home bound because I still like to get on the road, but I do different kinds of travel. I bought a rooftop tent for my car and I've been, during COVID, I told everyone, this is my private jet. I can get on there anytime, travel anywhere I want, not have to stay at hotels on there. And to me that was just wonderfully liberating and there's a lot to see just a couple hours away from us. We don't have to go to exotic locations all the time to get that mental simulation of meeting new people.

Polly Dawkins:

Yeah. Heather?

Heather Kennedy:

I've heard through the grapevine too, that there's going to be at least one travel company started by a YOPD person, by the way, that helps us plan our trips better with more space in between layovers, with spaces that we know have disability, you know, like things have been modified for us with people to meet us if need be with wheelchairs and accessibility for people that are bringing equipment with them and this is gonna be tremendously helpful. I cannot wait. So, stay tuned for that. That will be released sometime this year, I believe so that's exciting.

Polly Dawkins:

If you'll keep us in touch, then we can broadcast that to this community.

Heather Kennedy:

I will certainly.

Polly Dawkins:
That's amazing.

Kevin Kwok:

Yeah. Simplifying travel is the key if you're gonna do it. By moving to Denver from San Francisco, I opened up access to airports that I could never get to from the bay area across country. Like I could fly out of LaGuardia instead of JFK or I could fly to Nashville instead of Dallas in Washington, that actually cuts off an hour of commuting time. And you wouldn't think that's a big deal, but it does, those are the creature comforts that really make life easier for you.

Polly Dawkins:

Sree, do you have some thoughts? You mentioned just at the beginning that you were starting to travel a bit more and you've just gotten back from a trip.

Sree Sripathy:

Yeah. I think one of the key things is to talk to your doctor before you travel or whoever is managing your care and just get a check on your medication to, you know, see what you can maybe take on a plane or not take on a plane, how that affects you. I had an experience when I traveled my first international travel. After a while, after I was diagnosed with Parkinson's on my way to New Zealand and I passed out in the bathroom of the airplane because my medication just, I guess, affected me that way. So, they knocked on the door and they kind of helped me get to the bathroom. They had to lay me down, give me oxygen, which I think might have been overkill, but it's, you know, they gotta follow their protocol. And it was just a really intense experience for me.

And I had no idea what was going on. It never occurred to me that the medication I take at home regularly would've caused this for problem. And it's still not sure that it did, right? So, it's not conclusive that it did. But you know, this doctor said, my movement disorder specialist said it was a combination, most likely of stress from traveling, lack of hydration, you maybe did not eat well in time to prepare, and in combination with the medication and possibly the altitude as well. So, there were factors. So, my suggestion to anybody traveling is make sure you're well hydrated. It's tough for people with Parkinson's for anyone really in one sense, because the more you drink, the more you have to go to the bathroom and then you have to pull down your pants, pull up your pants, put everything back on. It's a lot of extra work. So, diapers, I'm sorry.

Heather Kennedy:

You wear pants? That'll get their attention. Sorry, keep going, sorry.

Sree Sripathy:

Heather.

Heather Kennedy:

Wouldn't that be fun to get on the airplane everybody gets on without pants and the next person that gets on says pants for sale.

Kevin Kwok:

Yeah. How many on international travel take sleeping medications like Ambien. That's a real danger on plane. You know, the flight attendants have a term for us, they call us Ambien zombies, those of us who travel taking sleep meds. But I used to take one on an international trip, right as I got on, so I could sleep through the entire flight land and go to work. But that's something as we have issues with sleep, I would be very cautious about the ambient zombie look.

Sree Sripathy:

Yeah, that's the medication that did me in was my sleep medication. Cause I thought I'm on an 18-hour flight. I think it was 18 hours or 12 hours. It was more than 10 hours. And I thought I really need to rest. And you know, there was no indication that this would be a problem. And I now do not ever take any sleep medication when I travel on the plane, I just power through. And you know, if you can, there are these lounges at the airport where you can pay \$60 an hour or if you have certain types of memberships when you land, you know, if you have the ability to go to one of those airport lounges, check in, take a nap, if you can do that, that is really refreshing and helpful. Even sometimes a 30-minute nap. You know, when you're really exhausted, gives enough energy for you to kind of be able to move and walk and start functioning again.

Kat Hill:

And Sree, I know that you have sometimes stayed at an airport hotel, something right, really close to the airport to give yourself sort of a buffer between. And I thought that was really smart. That's a tip that I thought was really smart. Your flight maybe gets in in the afternoon and you know, you're gonna be tired. So instead of planning the second you touch down, give yourself a buffer to the next day so that you can get someplace safe, kind of get reoriented to the schedule, get your medication figured out, then start your next day.

Sree Sripathy:

Yes, I do definitely do that. The other thing I do is I take taxis a lot more often now, which is more expensive, but the taxis they're, I don't have to use my shaky fingers and get an Uber driver and stand and wait and it costs a little bit more money, but you know, I don't have to do any of that stuff and using a phone when you're low on meds when you're OFF or even when you're ON and dyskinetic, pressing all those little tiny buttons can be very complicated. So I go back to analog, raise my hand, get a taxi. It works great.

Kat Hill:

I'd like to share something a little bit too. Ooh, I didn't, just about, I don't wanna forget to mention this, so I'm gonna throw it out just cause it came into my brain. Something that I wanna encourage folks to do. If you are thinking about camping and doing a lot on the road, there are, some of the state parks give discounts to people with disabilities. So, I know the state of California, for example, we will get half off our camp sites, the fees for those. So, while we might wanna spend a little bit to get the flight, I forget what it's called now, the CLEAR, TSA CLEAR. Maybe we can save our pennies camping, getting some discounts on campsites to be able to do the CLEAR. And there's also the America the Beautiful pass. So, if you are collecting social security disability you can apply for those things. And those are substantial savings, federal park discounts, museum discounts. And I it's important to consider those things cause it does add up.

Kevin Kwok:

There are also selected reserve spots closer to the bathrooms.

Kat Hill:

Yes.

Karen Frank:

We had a...

Kat Hill:

And often they don't fill up as quickly.

Kevin Kwok:

Right.

Karen Frank:

We had a question in the chat from Becca Miller about traveling with a child, a nine-year old alone and that she had some anxiety about traveling alone with a child. And I wanna know if any of you guys have some experience with that, cause that's a really hard situation to deal with.

Tom Palizzi:

Well, my wife travels with me and she considers me a child. So.

Heather Kennedy:

I hear you're famous when you travel, Tom.

Tom Palizzi:

I've heard that.

Karen Frank:

Yeah, Tom is famous when he travels. I gotta tell this real quick. So, my very good friend Darlene was in Hawaii, Tom, and you were on vacation in Hawaii and she recognized you from the Young Onset Parkinson's Council. And she was like, oh my gosh, that's Tom. And he has Parkinson's and apparently you were looking at her funny cause I think you recognized that she had Parkinson's cause if you got it, you spot it. You can tell. Right? So anyway, she was afraid to say something because she wasn't sure, but...

Kevin Kwok:

Think she's on board right now.

Karen Frank:

She is, she said a comment that she saw you in Hawaii, Tom, but anyway, back to Becca Miller traveling with a nine-year-old.

Kat Hill:

So, Becca, I didn't have young kids when I had Parkinson's, but I did lots of travel on my own with two to three young kids. And I just really scheduled what I did with them. I had them each carry their own backpack and at the beginning of the trip, I had things in that backpack, different things that we were gonna do at different hours. So that it wasn't, I was planning ahead for activities, things that I knew that I could stand. So maybe a mad libs or a card game.

Heather Kennedy:

Duct tape.

Kat Hill:

What?

Heather Kennedy:

Duct tape. Sorry.

Kat Hill:

Yeah. Crochet. I don't know. That really helped me and also helped the kids and they would get excited then on the trips before and say, mom, when are you getting out the bags? And I was like, not till we get to the airport. So, they'd be all excited about it. And just giving extra time because it just helped me to plan it in my head and not be anxious about it when I was by myself. And it also gave them something to look forward to. It kind of kept them distracted. I don't know if that helps at all Becca. I'll fly with you anytime, Becca.

Sree Sripathy:

Yeah. I'll fly with you too, Becca. I don't have any children, but I know from other people's experiences that, you know, one thing that was really helpful is to get priority boarding or early

boarding. Absolutely. And emphasize that you have a disability, and you have a young child as well. I've recently used the Parkinson's card. I didn't mention Parkinson's, but I said, you know, I need priority boarding because I, you know, have a disability. And that really helped with storing my luggage because you're down, walking down a very tiny aisle. So, if there's any freezing of gait or any anxiety, or even if you are just a person without freezing of gait, it's, you know, if you're less, if you weigh more than 20 pounds, it seems so hard to get through these aisles with a backpack or with luggage. And then I know Kevin mentioned, he doesn't like to check in luggage. I actually check in my luggage. Everyone has their preference, because of possible shoulder issues with lifting that stuff up high becomes more and more difficult for me. So, I prefer to make it as easy as possible. So, with priority boarding, you can avoid a lot of the stress of that. And then also it gives you a break when you're pulling out your luggage, just to kind of rest for a few minutes, without that rush to quickly leave, you know, and say, I have to de plane and all that sort of stuff.

Polly Dawkins:
Yeah.

Kevin Kwok:
This is a little bit of a nuance, but when you're on a plane, selection of seats is really important. Not everyone can upgrade. So, if you can't upgrade, you wanna get a little extra leg room. That extra leg room makes all the difference in the world on feeling cramped and tied in versus being able to stretch out a little bit. But the one caveat is when you board and you inform the people that you need extra help, they don't give you like the exit row seats anymore because they say, well, if you said you're disabled, you can't have it both ways. So be cautious of that when you play the disabled card too high heavily.

Sree Sripathy:
Kevin, I think you can donate your miles to the world, and we can all upgrade using your miles. I think that's a great idea.

Heather Kennedy:
Yeah. And before we get into the medication questions, which are great, and the travel tattoos from someone who likes to get a tattoo everywhere he goes. Like a Yakuza, you're gonna be covered from here to here soon. That's awesome. Let's talk about bladder control. Sorry guys. I had to bring it up. You know, I like to talk about pee, but I highly recommend for the ladies, there's something called Thinx. I don't usually talk about name brands, but there are millions of these different options. There's Thinx, there's Knix. There's let's see, Hello Hazel, Elvie, all kinds of things. They're washable things. And you can also add an additional pad just in case, because sometimes you can't get to the back of the plane or you get back there and there's a line and you're, you know, you're doing a little dance and there's nothing you can do after a while. So just make sure that you take an extra pair of underwear with you, gentlemen, and the ladies and everyone listening.

Sree Sripathy:

Yeah, in addition to what Heather said, they do have specific pants or underwear, not pants, underwear for women. They're not diapers. They're actually high absorbing underwear that you can wear. They're usually black in color. They're a bit expensive, about \$80, I think for two of them. But they work really well and they're fairly stylish. So, that can often help also with, you know, if you feel kind of awkward about wearing something like that, that looks more like a diaper. These work really well. So, I've heard. I've never tried them, but I just discovered them.

Kat Hill:

I also wanna share along the no pants conversation, I don't wear pants when I travel. I usually wear a dress or a skirt so that it's easier to get off and on. And guys, you know, it's a wide-open world there, so you can join us in the skirt wearing if you'd like. Heather won't have anything on, I will have a dress and I'll bring an extra one.

Tom Palizzi:

That's a good point that you make. Cause I do, I'll wear like just elastic waistband pants, or I have some nice pair, lightweight travel pants, real easy to deal with.

Heather Kennedy:

We're looking good people. Somebody called me ma'am the other day. She said, ma'am, are you drunk? I was more mad that she called me ma'am than whether she asked if I was drunk.

Kat Hill:

Right.

Heather Kennedy:

Did you call me ma'am?

Sree Sripathy:

Heather, I'm gonna start calling you ma'am all the time.

Heather Kennedy:

Oh ma'am. These kids have already really ruined my international travel girl vibe. And now I have Parkinson's that's really ruining my international travel girl vibe. But if you call me ma'am, it's game on.

Sree Sripathy:

Yeah. The other thing I'd mention, I think somebody referred to this, making sure you're hydrated, but to also bring food with you while you are traveling, I have found that I always think I can get something at the airport and pre COVID, you could. Now it's much more difficult to get anything. And even at 8:00 PM at night, there's nothing open oftentimes. The other thing

I used to take would I take a lot of nuts and chocolate bars. I find that to be a lot more for me now because of chewing and biting and swallowing. So, I would suggest taking easy to digest foods and things that you know, that work for you, and I'd make that definitely a priority. My third suggestion is, is when the air flight attendant, stewardist? I don't know what they're called, whatever they're called...

Kat Hill:
Flight attendants...

Sree Sripathy:
The lovely people who bring you snacks. You might wanna bring a container to pour the drink in that has a lid on it because a couple of instances, my dyskinesia got a little crazy. I'm sitting in the middle seat and that tomato juice spilled all on me and all of the two people next to me. So, then I had to mop it all up. It was actually, they were very kind. If you know, a little bit perturbed, but yeah, learn that the hard way. So.

Polly Dawkins:
Some airlines have covers for children. So, you may just ask for a cover on your drink too.

Karen Frank:
I also travel Sree with a microfiber cloth sort of like the size of a large wash cloth. They're great for multipurpose. You can clean your glasses with them. You can wipe up a spill. They're very absorbant, you just keep 'em in your bag. It's great.

Sree Sripathy:
Oh, that's great. We should send out links to some of these products. Kevin's cane, and the micro fiber cloth and that sort of thing.

Tom Palizzi:
Or just a little package of Clorox wipes, you know, we get on the plane, we wipe down everything around us and all the tabletops.

Sree Sripathy:
Just make sure you don't use it to wipe your face.

Karen Frank:
So this is a completely different...

Kevin Kwok:
You froze Karen.

Sree Sripathy:

I think Karen's frozen.

Karen Frank:

Let's talk about poop. Right when I was talking about poop, I froze? I was gonna say let's talk about poop. Cause we talked about pee, constipation when traveling. I get that because I think I get dehydrated on the airline. I don't, I found out that you could buy Miralax in packages that are already pre dosed. You can just tear 'em open and pour 'em in your water.

Kat Hill:

Yeah, I think that's helpful. I also think what I try to really do. I know that if I get behind on water or fresh fruit and veg, I get behind. And so that's some of what I try to, it's like that's some of my medicine and that's some of my routine while I'm gone. At one meal, I'm sure that I have like an apple and fresh carrots and I just that's part of my routine. And it really does help my digestion some. Again, a lot of it's planning and knowing what your own routine is and seeing if you can mimic that some. I think that's important. And I also, if anybody else is traveling with family, part of what's hard with Parkinson's is that our routine is different than it used to be. And the keeping up part is hard, and you don't want to A, overdo it to keep up or hurt ourselves doing that.

And, and I know that I've been learning to accommodate for myself when I'm planning to travel with my family, to have activities that I can do where I'm still having a really good time and engaged but I don't feel like I have to keep up with everybody else. And I've been learning how to just kind of keep a journal and a little sketchbook. And it helps me to take a break. My family's comfortable going on ahead without me. And they know I'm having a good time and still engaged. I usually sit down somewhere at a cafe where I can order a cup of tea. They know I have a bathroom. And then they come back and join me when they're ready. And that allows us all to enjoy ourselves and me to not feel like I'm slowing everybody else down. So other people may wanna take a book with them, you know, or listen to a podcast, but think about that instead of not going, cause you think you're gonna slow everybody else down. Maybe find ways to enjoy things, but maybe in a little bit different way. Anyway, that's my soapbox for the moment. Sorry.

Polly Dawkins:

Great suggestions.

Kevin Kwok:

You know, those of us who travel for work, one of the things that I would suggest is take an extra day to enjoy yourself in the places you go. Often, I find myself going to, you know, across the world, just for one dinner meeting and flying back. And that's just such a waste of time. You know, when you really think about quality of life, slow it down a little bit, go to a museum the next morning before you fly home, you'll find that it's much more enjoyable. It doesn't really take that much more time to build that extra little half day in.

But there is another thing that I wanna chat about, which is sort of an unpleasant thing, but it's something that, you know, when we travel abroad, be careful that we are targets. Pick pockets and people who look and prey on people like us and I really encourage as you're walking, not to take a map out in public or look at your phones, your wallet is an easy target and pick pockets are so good at working in teams. I was just in Barcelona a couple years ago before COVID hit and had my wallet stolen.

Heather Kennedy:
My son just got his stolen in Madrid.

Kevin Kwok:
They're really good. They work in teams.

Polly Dawkins:
So, let's segue to answer a question. That's come up in the chat, which is as you are traveling, especially if you're traveling via an airplane and you're going through multiple time zones or you're going to Europe or lots of time zones, how do you manage your meds? How do you manage traveling through that many time zones with your medicines?

Heather Kennedy:
Go ahead, Kat.

Kat Hill:
I know that what I do is that when I'm trying to get on the new time zone, I dose, let's say I'm awake for 20 hours or 24 hours, or trying to be awake for 24 hours. I might dose my daytime dose that way on the way there. And then I'll take my long acting when I'm supposed to be asleep. And then when I come home, I do the opposite. So, I take my nighttime meds as I'm traveling and switch over. I think it's probably worth having a little bit of a dialogue with your provider if you have a complicated medication regime, this is not meant to, you know, suffice to be medical advice for you. But, I think there's, I've heard people doing it different ways that has worked really well for me consistently. And I've done, I was gonna say time travel. That's not, I haven't done time travel.

Karen Frank:
Wow. I wanna do that, sign me up.

Kat Hill:
I'm going the wrong way!

Heather Kennedy:
How do they know which way we're going?

Karen Frank:

Do you have a DeLorean Kat?

Tom Palizzi:

I know a guy who does.

Kat Hill:

Forgive me. It's been a long week. Anyway, that's what I do. So, what does everybody else do?

Kevin Kwok:

Actually, there's a really good article in the New England Journal of Medicine on managing jet lag with melatonin. And supposedly all of us are taking it incorrectly in the sense that we take it as a sleep med, instead of using it as a med to sort of adjust your time cycles. And so Caden says exactly that, you should take it at five o'clock at your destination time and then expose yourself to sunlight. That really the proper way to take the melatonin, but very few people can work out the time zone differences. I know I have trouble.

Tom Palizzi:

It depends on which way you're flying and all that, how far you're going and stuff. But what I generally try to do again, this is general and not a solution for everybody, like Kat pointed out. I try to get myself on the destinations timeframe as soon as I can. And usually that involves me maybe skipping a dosage over the evening or the nighttime. Like if, when we flew to Australia, you know, I skipped a whole day and then just jumped on the daily meds the morning when we got there and I was actually better than I've ever been in that case. But that's just, again, a very dependent thing on what you take, what your cocktail's like and et cetera. So.

Sree Sripathy:

Yeah, I think for me, when I was traveling internationally, or even from the east coast to the west coast, which I've done quite frequently recently, and I'm traveling, I think every single month to the east coast this year, I have no idea how that's happening, but I often have side effects from medication, that means as soon as I take a pill, depending on the pill, I get sleepy or fatigued within minutes. So, for me, timing is of essence. I cannot follow the same schedule that I do. So, I often just listen to my body and make the best of it and take one full day of rest, maybe two days of rest, if possible. So, if you have a busy schedule, meaning you're landing, you're attending a conference the next day. I think Kevin addressed this earlier. Try and take some extra time, you know, show up early, Kat also mentioned this other people have as well, give yourself that time and write down what your normal schedule is.

You think you know what your normal medication and eating and drinking schedule is, but a lot of us actually don't know and then figure out what time your plane is landing, what time you might get to the hotel, map all of that out in advance and figure out what the best time to take

your med to be. That has been something that's been really, really helpful. And quickly somebody asked in the chat, I think it was Heather, what do we all do for medication? How do we take it? My fingers sometimes get too shaky and too stiff to use a lot of those things. So, I have spent a lot of money on different mechanisms and different bottles and different things. And honestly, nothing has really worked for me. So now I just take all of the bottles with me, with the labels and that actually works well because if I'm traveling internationally, particularly to countries where English is not the primary language and they don't speak English that well as a second language, nor do I speak the language well, trying to negotiate with the immigration office or somebody else as to what medication you have and showing them the card, they can also dispute the card.

So, I take the pill bottles with me full on. They jingle and they jangle in the backpack. That's fine. I never check in my meds. I take everything with me, everything. I'll stuff it in my bra if I have to.

Tom Palizzi:

Me too

Sree Sripathy:

It's a very lucky bra.

Karen Frank:

I had a good suggestion and I will do this whenever I travel internationally to a country where the language is different and I can't point to letters for example, of the traditional alphabet that I'm used to. When I was in Japan for the World Parkinson's Congress and we were walking, they gave us these little cards, which were wonderful, that said I have Parkinson's in Japanese and various other things. If I need help, I have Parkinson's. And I thought, oh, I probably won't need to use this card. But every day when I went out, I stuck it in my pocket. I was traveling with another friend with Parkinson's, who fell off the curb and hit his head. And he was a little out of it. And people were coming over, I was anxious and my tremor was shaking and he was, you know, not doing that well. And I remembered, I had that little card and I pulled it out and said, I have Parkinson's. And I pointed at him, and I just handed them the card. And they were like, oh yes, I know what to do. They actually called for help. And they were able to speak Japanese and tell the help that arrived that he had Parkinson's, it was very, very helpful. So, I will always do that with my Google translator. I'll just print out a little card. I have Parkinson's.

Tom Palizzi:

That's really, that's really smart thing to be prepared for everything. I mean, as much as you can think of. And I've seen that so many times, Karen, I was in Washington DC and a very good friend of mine with Parkinson's fell on her way back to her hotel. And we had walked her most of the way there. But as we, as she said, she could get down the last block to get there, right square on her face, broke her nose, a couple of teeth. It was a horrible situation. But again, you gotta plan on that happening, cause that's very, it can very likely happen, especially in countries

where they don't take care of their sidewalks. Not that they do a great job here, but you're not a lot more prone to find a little lip in a sidewalk in Rome, for example, than say in downtown Denver.

Kat Hill:

But well, it's unfamiliar. That's part of it. So no matter how well they tend things, it's a city that you're not familiar with, a hotel you're not familiar with and you know, a campground you're not familiar with. Somebody asked in the chat about DBS. I think, the other thing, you know, a medical alert bracelet, make cute ones now. I have a kiddo that's a type one diabetic and I think it's important for us to consider those things so that first responders can help us in a way that's safe for us, also, just to be thinking about if you're traveling.

Heather Kennedy:

Yeah. Why aren't there more beautiful bracelets for us? I think somebody needs to design that. Something that maybe could be cross referenced with say, what is the medical system that we're working on, Kat?

Kat Hill:

The Help Work Taskforce

Heather Kennedy:

Yeah. All of the things if they could be cross referenced somehow that would be great. I wish.

Kat Hill:

Yeah. Hmm. That's good information. Yeah. Good feedback.

Karen Frank:

Kevin, what were you gonna say?

Kevin Kwok:

Yeah. I actually had another comment. Many of you on this panel and I know many of the audience use CBD and THC and with laws becoming more lax, you know people are starting to... yes, exactly... If you're traveling overseas do not travel with THC. I mean, I've accidentally thrown stuff in my suitcase and left it there and you just do not wanna get into that situation when you're traveling internationally.

Polly Dawkins:

Great point. I have a visual of the pill container that...

Heather Kennedy:

I love those.



Polly Dawkins:

This is the bigger size of the GoTubb. It opens with one hand, you can also put your...

Kat Hill:

Oh, that's cool.

Polly Dawkins:

This is the larger size, but one hand just squeeze it. And yeah. Snacks...

Kevin Kwok:

Where did you get that Polly?

Polly Dawkins:

Jackie put the link in the, yeah, Tom has the smaller version.

Tom Palizzi:

That's cause you showed them to me.

Polly Dawkins:

I love these. These are so great.

Karen Frank:

Oh, Go Tubb.

Heather Kennedy:

I've done some little advertisements on my own for them, but I don't ever put them out there because I don't wanna promote any particular brand, but they really are the best. They really are. They come in different colors too. So, you can just quickly look into your pack and keep one in your pocket. They're water resistant. I mean, it's really nice.

Tom Palizzi:

I just posted a note, sorry. I just posted a note that said bring extra meds of course, when you travel, I usually bring one and a half times what I need. So, and again, like Sree, I'll bring it mostly in just the bottles cause I used to try to arrange it all. And I thought this is BS. Just throw it all in a bag and shove that bag inside my backpack and shove that bag in my backpack and it's always on my body. And then the other thing is take extras of these and hide 'em in your wife's purse or in your suitcase or someplace else. Cause if you're like me, you're gonna walk out the door and you're in line to go see the, I don't know, the Vatican or whatever and you forgot your pills. Right? That happens to me all the time, so stash extras.

Kevin Kwok:

The pope's not carrying it for you?

Tom Palizzi:
What's that?

Kevin Kwok:
The pope's not carrying your meds?

Tom Palizzi:
No, not usually.

Kat Hill:
Not yet.

Sree Sripathy:
The other thing I'd suggest that I learned also the hard way is make sure that if you get your meds online, add an additional address, if you're staying with family or if you're traveling somewhere else where you know someone, you can add their address as an additional address. So, meds can get shipped to you in case of an emergency. Doing it during a crisis or during a, oh my gosh, I ran out of my meds is actually stressful. So, think about that. Also, if you can, and this is not easy to do in the US, and it's probably difficult to do in some other countries as well, is see if you can get three months of medication in advance. I often need a special doctor's directive to do that, but at least when I was with Kaiser, they accepted it saying it was specifically for travel. And I still keep that because honestly, having to get your meds refilled every single month while you're traveling in and out or for any reason is, you know, it's another level of anxiety. So, I always carry, I don't even carry twice the amount of meds I need. If I'm going anywhere, it's the minimum of one month's worth of meds. I am just paranoid. I can't go without them. If I'm traveling somewhere for more than a month, I carry two months.

Karen Frank:
I'm the same way. I agree. I just ran into an issue where I was gone for eight weeks and I had to order meds through express scripts. So, I changed my address on express scripts to have them mailed to Colorado, but I forgot to change it back. And so, I had an auto refill that actually sent my meds to the wrong address. So, I don't use auto refill because I don't feel like I'm in control. And I'm so obsessive Sree about my meds like you are that I don't feel comfortable with anything being automatic. So, I wanna be in control of it. So, I actually now remember to change my express scripts address back to my home address so the meds got shipped to the right place.

Sree Sripathy:
That happened to me just two days ago. I forgot to change the address back. And I'm like, oh no, my meds are being shipped. But luckily, it was shipped to a family member's house. So,

they're gonna ship it back to me. So, you do have to remember that and with brain fog, that can be a little tricky, but you know, post-it note right on your forehead, maybe...

Kevin Kwok:

Hey, don't forget to exercise when you're traveling. I know you joined a gym Karen, but it's so important.

Karen Frank:

I also use my Oculus when I'm traveling, I put it in the car and I do my...

Heather Kennedy:

What'd you call me? An Oculus? What is this?

Karen Frank:

You're an octopus. Oculus, Oculus. Have you guys exercised with an Oculus?

Heather Kennedy:

Yes. It's terrifying

Karen Frank:

You can do yoga on the moon. What are you guys doing? You have to check it out. It's great.

Tom Palizzi:

There's exercises you can do in the seat of the airplane, too, so don't forget to stand up and walk around the plane a little bit.

Kat Hill:

I also take, I get a lot of dystonia if I sit too long, probably a lot of you do too. I have a small, I use often a roller, like a rolling pin almost on my shins. I take a little small dowel to roll out my shins. Looks funny, you know, but it's about that long, but it's about a one inch dowel that I sanded down and I just I'll roll out my shins or my calves if I'm having trouble. My husband sometimes will work on my feet if I'm having trouble, but getting up and moving around and staying hydrated and staying on schedule with my meds seems to help that the most.

Kevin Kwok:

Or a tennis ball really works well.

Kat Hill:

A tennis ball. That's a good idea.

Sree Sripathy:

You can also bring a massager, something I think I've used recently, which is a theragun. They have a travel version of it for \$199. It's a bit pricey and it's not always the easiest to use, but it's better than a lot of other things. It really gets rid of a lot of tension everywhere.

Heather Kennedy:

Nice. And if you have tension from someone that you're traveling with, you can always tape a vibrator to their water bottle as you're going through the TSA. That'll stop 'em for a while. It's a pro tip. I've never done anything like that.

Karen Frank:

You've never done anything?

Kevin Kwok:

You're thinking it.

Kat Hill:

I think our takeaway is, be careful if you're gonna travel with Heather.

Sree Sripathy:

Yeah. And don't wear pants. Don't wear pants.

Heather Kennedy:

Parkinson's! Sorry! But in all seriousness, if you do use DBS, I was mentioning in the chat. Make sure that you have this on your person. If you lose this, you're kind of screwed.

Tom Palizzi:

Oo yeah.

Heather Kennedy:

Especially if it gets in the wrong hands.

Karen Frank:

Didn't you lose it once Heather? I remember.

Heather Kennedy:

That must be somebody who looks like me. My doppelganger.

Sree Sripathy:

I wanted to point out a couple of the comments. I think Amy mentioned this and I know Heather mentioned this and this kind of relates to what Karen was saying earlier. If you're traveling internationally or anywhere in the world, what Parkinson's has given us is a huge community. There's pretty much anywhere in the world we can go where we can meet

someone who has Parkinson's disease and that they understand what we're going through. So, if you're going to Sweden, I think Amy mentioned that. Or if you're going to Amsterdam or I mean, it's the Netherlands, but Amsterdam, whatever, contact anybody you know there with Parkinson's, there are Facebook groups, there are online groups and let them know, hey, I'm coming, would be great to meet up. Maybe we can go to the museum together. That's a great way to extend your network and have a local person who knows the ins and outs. So, they're like watch this cobble step where David was, the statue of David was here. Don't fall over, whatever it is. I think that's a great idea.

Tom Palizzi:

And if you happen to see me or one of my other famous colleagues here, say hello.

Karen Frank:

Please, please.

Heather Kennedy:

An autograph.

Karen Frank:

In Hawaii.

Sree Sripathy:

Tom is gonna be in Hawaii all the time now.

Tom Palizzi:

I'm moving in about an hour. Anybody wanna go? I'll drive.

Kat Hill:

Somebody also brought up, how do you deal with equipment? And right now I don't travel with equipment, but my dad did. And what we did was call ahead and had equipment rented where we went, instead of traveling, trying to take things with us having equipment, there's often rental companies that you can rent from and they sometimes will even bring it to your hotel. So just food for thought, if you're traveling and you need a scooter or you need a certain accommodation, think about that on your trip at your destination.

Heather Kennedy:

And whatever you do, don't drink.

Sree Sripathy:

Don't drink with Heather, I think is the subtext right there or better yet drink with Heather and have the time of your life.



Karen Frank:

Don't drink out of Heather's water bottle.

Kat Hill:

Oh gosh. I hope this has been helpful, I've learned a lot about Heather.

Tom Palizzi:

A lot more.

Heather Kennedy:

You know who you won't be traveling with. Kevin just mentioned a cavity search, but anyway, onto brighter subjects. Oh hello Davis.

Karen Frank:

Oh, yeah Davis is with us. Hi Davis.

Heather Kennedy:

We're just talking amongst ourselves live on your webinar.

Karen Frank:

Way to represent.

Polly Dawkins:

This hour has gone by so quickly. What great advice. What great laughter. You all have given me in my day and hopefully our audience here. We're gonna come back together again next month. If you all in the audience have topics that you would like this group to talk about, please share them with us. You can do that at blog@dpf.org. Tell us what you would like to know about. In the meantime, we will be gathering links. We will be, all of the suggestions here, the suggestions from the chat. It may take us some time, cause there's been so much robust content. We will get that out to you with transcript and video as soon as we can. In the meantime, any last quick words of advice, one thing you'd like to leave folks with?

Kat Hill:

Keep traveling if it brings you joy.

Tom Palizzi:

Absolutely, yeah.

Sree Sripathy:

Travel with Heather.

Polly Dawkins:



Wonderful, huge amount of gratitude to all of you. And to those of you who showed up today to watch. Thank you. And we will be back same time next month, third Thursday at this same time, we will see you then. And thank you panelists. Really wonderful suggestions.

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