

wHolistic!™ - Introducing Neuropalliative Care - Dr. Benzi Kluger

Dr. Subramanian: --socially connected to a virtual connection world. Hope everyone's staying safe out there and I know we're really in just quite unprecedented times nationally, internationally, so many changes, and so hopefully everyone's keeping their anxiety levels down, sleeping well, trying to stay connected, and exercising out there and trying to stay sane and digest it all. I'm really excited to have our speaker here today, Benzi Kluger who's a friend and such an inspiration for all the things he's doing. I wanted to bring him to our group here today and share some of his wisdom and inspiration. Benzi has moved recently from the University of Colorado, which is where he trained for his residency, over to the University of Rochester, and he has a dual appointment both in palliative care there as well as in neurology and really has some interesting background. We'll learn a little bit about his journey and about what he's doing, what kind of things he's advocating for and how he's trying to make a difference for patients. Welcome Benzi, thanks for joining us.

Dr. Kluger: Thanks for having me!

Dr. Subramanian: So maybe Benzi we can start with just learning a little bit what urged you to go into neurology and then some of the fellowships-- because you've had a few fellowship

trainings. Maybe you can tell us about what inspired that journey up until fellowship initially
Dr. Kluger: Yeah sure. I guess I started medical school actually thinking I was going to be a psychiatrist and became really interested in how the brain works. I didn't know anything about neurology before that and got into neurology, was very interested in things like free will and Oliver Sacks and all of those kinds of things, and I did what's called behavioral neurology which is the part of neurology that is most concerned with thinking and memory. While doing that, I developed an interest in fatigue. I actually developed that during a kung fu class. They have you do various things. I don't know if people are familiar with horse, but it's basically holding a squat. And 30 seconds into that squat, I thought my legs were going to explode. The teacher came by and told me to keep doing it, and when I kept doing it, my legs didn't explode. And it got me curious about where fatigue was coming from, and it looked like a lot of it was coming from my brain and not for my legs. As I got interested into fatigue, I started learning more about Parkinson's and how big a problem fatigue is for people with Parkinson's. And so I ended up doing a second fellowship in movement disorders. At that time, I then thought my career was going to be about understanding fatigue and the physiology of fatigue and how that's created in the brain. Then when I finished that and took up my adult job at the University of Colorado, again I had a big shift and that shift happened because when I was a fellow and when I was a resident, if I saw somebody with Parkinson's or corticobasal degeneration or something like that, it was just a snapshot, and I could make that diagnosis, and I could get the right medicine started or whatever. When I started seeing people long-term, it was no longer a snapshot, and I got to see the tragedy of Parkinson's and Alzheimer's and other illnesses play out over time. It really forced me to confront things that I didn't learn about during my fellowship-- different sources of suffering, how do you keep hope in the face of an illness that's not curable, how do you support caregivers, how do you talk about death and dying. That kind of led me on my own spiritual journey-- and we can talk more about that if we want to-- which included Zen Buddhism and spending some time in a monastery. And it also took me into the world of palliative care, and that was really where I have kind of found a home in medicine, is being able to take care of people living with serious illness as opposed to taking care of diseases. That's kind of how I ended up where I am right now, and I'm really really happy to be here.

Dr. Subramanian: That's amazing. I think we share a lot of those parallels, and some of the people that we brought on this series have been a little bit more on the spiritual side of things and not looking at disease as just one diagnosis like Parkinson's or a symptom like tremor, but really looking at the whole picture, the whole person and this spiritual, mental, all these different

aspects of their well-being. Maybe you could tell us a little bit about that journey with the monastery and how that influenced you, and then I definitely want to hit on some of these other areas. We'll talk about fatigue, we'll talk about hope, and I also want to bring in a little bit of the pieces that you're really doing around the neuropalliative initiatives and things like that. We'll hop around a little bit so, we'll have a journey.

Dr. Kluger: Yep that sounds good. The monastery came up, I would say a year or two after I started my adult job at the University of Colorado. I could actually remember some of the patients that led me to it. I was seeing a woman who had multiple system atrophy, which is kind of a cousin of Parkinson's disease but worse in a lot of respects, and her and her husband had come to see me. She wasn't depressed, she was just sad. I didn't even have words for it. In medical school, I learned about depression, I learned how to prescribe Prozac, but this woman actually seemed to have a good reason to be sad and had a good reason to be hopeless, and I didn't have tools for how to deal with that. I had other patients who were clearly dying of their illness, and I didn't know what to say. I felt as helpless and hopeless as the patient in front of me. Actually, with the woman with MSA, I can remember specifically one visit where her husband was taking her to a medical hypnotist and this hypnotist was asking her to make positive affirmations in front of a mirror that, "I'm getting better every day," that "I feel good." I asked her how she felt after she said those affirmations, and she told me, "I feel like shit." It was just kind of eye-opening for me, and I actually got to the point of wondering if I even went into the right field because I felt like the things I was offering people wasn't what was really needed to help them. I ended up going to a monastery just because I knew a little bit about Buddhism. I knew that it was a religion that took suffering seriously, and while I was at the monastery a good friend of mine now Matt Zeppelin, I was working with. He was a monk who volunteered in hospice, and to me that was mind-blowing because I was a doctor and hospice was a very scary place for me, and here he was, a monk without any "training" and he was with people who were dying. I asked him, what did he do, how I was he able to do that? And his answer was that the most important thing was to just to be present, to be open and to acknowledge that he too was somebody who was getting old, who was suffering, who had experienced illness, who was dying. I think in our society, we kind of divide people into, I'm healthy and well, and you're sick and dying, and that can be a very lonely place. I think once we kind of removed that barrier and became really open to my own suffering and to my own mortality, I was able to talk to other people more openly about that, and there was actually a real palpable shift in that. I felt comfortable asking people questions that I didn't feel comfortable asking them before. I could ask people questions about, are you afraid of dying? What's the hardest part of this for you? And I could listen to that, and I could be with what they said. I think that's the key step, because if you can stay present and not run away from it, then you kind of open up the space in the room to help. But if you're closed, and if you're looking for an answer, and if you're wanting science and medicine and pharmaceutical to get you out of that jam, then you're kind of stuck. So that really was a turning point for my career, and it really opened up I think not just new ways for me to see the person in front of me, but new ways for me to see myself, and that I no longer had to fit this role, which never was a good fit for me of being just a doctor. I could show up as Benzi, and I could bring my past and my knowledge and courage and fears and uncertainties to the visit, in addition to the things I learned in medical school.

Dr. Subramanian: Yeah that's very profound. I remember, Benzi, you and I spoke-- and I don't know if you remember this-- on the phone a while ago, I think it was about six or seven years ago, where I had a similar journey, where I've learned what we do well in Parkinson's treatment and what we don't do well, and was sort of at an impasse. I feel like there's a lot that we're not doing for our patients, and how do we think about this in a different way. You told me that you were frustrated by some of the experiences you had had through fellowship and were feeling like a lot of the time we were telling our patients that they just had to learn to live with these diseases, it's like you just have to learn to live with it, but we weren't really giving them tools to

be able to live with these diseases or the situation. I think you wanted to help fix that. I don't know if you remember telling me that, but I found that really inspirational. I think we've brought together a group of like-minded doctors, not just in addressing the issues of our Parkinson's patients under the umbrella of neurology, but trying to figure out how to bring like-minded folks in to help with neurological diseases in general. So I think maybe we could speak a little bit about the Neuropalliative Society and why you think it should exist. Maybe define it a little bit, why you think it's an unmet need and help our patients who are on this call understand how they can maybe advocate for some of these things and get involved.

Dr. Kluger: Sure, yeah so I guess to jump ahead in this journey that palliative care-- and I know you've talked about palliative care before this group-- but just briefly it's an approach to care where the goal is to take care of the person in front of you including spiritual, emotional, social, all aspects of that person. Over the last 20 years this has become better integrated into cancer care. It's still not where we would want it to be, but if you go to a cancer center anywhere in the country, they're going to have palliative care. They're probably going to have a summer camp for your kids and a book club and writing clubs and in all kinds of things. If you go to a Parkinson's center-- the best centers in the country, you don't get any of that, same thing if you have Alzheimer's disease, even ALS. So I think the mission of this society is that we need to raise the standard of care for all people affected by neurological illnesses. That includes the person living with illness, so called patient, and includes their family because illnesses like Parkinson's don't just affect one person. It also includes the clinicians-- the doctors and nurses-- because we're not given the tools, we're not taught the tools that we need to really address this suffering the way that we should. That's really the central mission of this society. Part of the reason for starting a new society-- as everyone on this call knows-- is that Parkinson's disease and Alzheimer's and these other illnesses are very different than cancer. The needs of somebody with Parkinson's are very different than the needs of somebody with cancer, and so part of the reason for starting the society is to recognize that people living with neurological illnesses really have unique needs and that we need research, we need clinical programs, we need education, we need advocacy, so that we can best meet those needs. As Indu mentioned, we're getting this society off of the ground. We are intentionally making this society international because we need perspectives from all over the world. We're making it interdisciplinary with nurses and geriatricians and neurologists, and I think very importantly, we're making the society open for people living with these and their care partners, because that's an essential voice that we need if we're going to do this right. Indu is part of the society, so as we get things off the ground, and we get the website up, and we have membership available in meetings, we will absolutely keep everyone on this call informed because we would love to have you join us. We think that this is an important movement, that it's likely going to be a grassroots movement, but we're already gaining traction and changing the way we think about and changing the way we take care of people with neurologic disease.

Dr. Subramanian: Yeah that's really important. How can patients advocate for this more? Maybe tell them a little bit about what you foresee the role of patients in the society as being. Because I know honestly, Benzi, you and I have done work over the last I think five years, and when you were in Colorado, you had a tremendous patient advocacy group that you worked with there, and you worked day in and day out with patients to help them guide you I think in a very interconnected way to get care that was needed for patients. How do you foresee this being kind of a symbiotic kind of beautiful thing that patients can feel connected to and help themselves, help you?

Dr. Kluger: Yeah, so I guess there's a few ways. One, it is advocacy-- so being involved with the society. I think some people on this call maybe have been involved with the Parkinson's Association PAIR program: Patient Advocates In Research. So there's the absolutely room for advocacy and I think this is an area where we really need to hear the voice of people living with these illnesses because-- well I'll tell you, I think a lot of the pushback on palliative care-- when I

give a talk about palliative care, people are ready to sign up for it, and they ask me why isn't this obvious to everyone, why haven't we done this 20 years ago? And the two answers: one is the insurance companies, and we have to kind of change the standards and change expectations. And a second one actually is physicians, that a lot of physicians still have-- I would say-- old-fashioned notions about what palliative care is and hospice and when it should start and who is it for, and so we need to educate them, and part of that will be through this society. There are actually ways-- and we're actually doing this in one of the studies that we're doing right now-- that you could come in as an activated patient and help educate your physician. To give you a few examples of that, when it comes to non-motor symptoms-- things like depression, fatigue, pain-- those are things that you may need to bring to the attention of your physician. Your doctor may not ask you about those, but if you bring them in they will be able to handle it. If your doctor doesn't have a checklist, you come in with the checklist, and you make your doctor a better doctor. That's what I mean by being an activated patient. Doctors actually can fill out paperwork for power of attorney, for advanced directives. They may not remember to do that, so on your checklist you can bring that in, and you can ask them about it. If that doctor is not comfortable with that, that starts to become a push for change because now that doctor hears that, and maybe you're starting to hear that from multiple patients, that "hey I need to start learning more about this." There are absolutely resources that doctors can learn about that. You might ask for palliative care, you might ask for a palliative care referral. Again, that's going to plant this seed in the doctor that you're seeing that there's stuff going on that they don't know about. If you're going to certain centers like Colorado where I was or Rochester that the physicians may be on board with that-- but I would still say most places in the country are not at that stage, and so I think some of this is going to be a grassroots level. If I could jump ahead a little bit, we just got a very exciting grant from the Patient-Centered Outcomes Research Institute. What this grant is, is we're partnered with the Parkinson's Foundation to make palliative care the standard for all of their centers of excellence across the world. I think over the next three years through this grant that that's really going to be transformative to making this a new standard for the whole field because those are where people train. Those are where over 200,000 Americans get their care. They're really the leaders in their region, so I think this is really happening. We definitely need the patient and care partner voice to let physicians know that not only is this okay, this is what we want. Because I think a lot of times doctors are afraid that if they bring up palliative care or if they bring up advanced directives, that they're going to take away your hope, and my experience has always been, when I bring up these topics, people feel relieved, they feel heard, they feel seen, and I think you have to let your doctors know and to encourage them that this is actually the right direction for them to go.

Dr. Subramanian: That sounds good. Now Benzi, you not only talk about this from a clinical perspective, but you've also been doing some pretty groundbreaking research. I'd like you to tell us a little bit about the PCORI study and the publication in-- I believe it was-- JAMA Neurology. And then maybe you can talk a little bit about the future of that kind of research.

Dr. Kluger: Yeah absolutely. So I think it was in 2014. We had started our clinic in 2013. We did a couple of studies that showed that people living with Parkinson's disease had palliative care needs that were actually at the same level as patients with cancer, and that these palliative care needs-- things like spiritual well-being, like grief, like symptom burden-- contributed to that patient and their caregiver's quality of life. So if our goal as a movement disorder society is to optimize quality of life, we are not going to get there if we don't address palliative care. That became the foundation for us to write a grant which we got to do a randomized control trial where we compared outpatient palliative care-- so that included a neurologist who is doing palliative care and a nurse and a social worker and a chaplain-- to standard care, which is you see a movement disorder doctor, you see your primary care physician, and then whatever else happens is what happens. Our contention was, was that by having an organized team, that things were not going to fall between the cracks as much and that patients were going to have a

better quality of life and that care partners we're going to also do better. We felt that under usual care, that when it came to things like spiritual well-being and care partner support and difficult emotions, that the care partner and the patient we're kind of on their own to figure things out, and that they might get lucky and find a good support group or their social worker, but more often than not they didn't find those resources. So at the end of the day, when we compared the results of this study, I would say the outcomes were overwhelmingly favorable for palliative care. Patients had better quality of life, caregivers had less burden, caregivers had less anxiety. Patients had better treatment for their non-motor symptoms like pain and constipation and depression. Patients had better spiritual well-being and grief. They did a better job with completing advanced care plans. So we really showed I think pretty definitively what we all knew, which is that palliative care is a good idea for people with Parkinson's. I think the question now is not *if* palliative care is the right thing to do for people with Parkinson's, but how do we do it and how do we do more of it? So we're right now in the middle of a study that's funded by the NIH, which is a community-based study in which we are training neurologists in the community-- there are 20 neurologists actually in Colorado and Wyoming and California, some of them in rural areas-- and we're training them how to do palliative care, and then we're using virtual house calls-- so telemedicine-- to provide the chaplain and social work and other support for their patients. We're about four years into that study, so we're almost done with the study, and then we'll have the results. I can tell you that qualitatively-- so before looking at the data-- that both patients and neurologists really like the study. I think people are really getting a lot out of it. When we started the study actually, telemedicine wasn't as common as it is right now. So COVID, coronavirus, has really kind of accelerated things in a direction that we were going anyway. We were already going in this direction three years ago, but I think it's accelerated it. We'll see if this model of care can work, and if it does work, this is another thing that the Parkinson's foundation has committed to supporting. So they would also commit to supporting, providing this extra layer of support, through their centers of excellence, so we're excited about that. I think that's really kind of the next frontier with neuropalliative care, is how do we make this the new standard, because not everybody is going to be able to get their care at the University of Colorado or at the University of Rochester. So how do we develop models of care that allow us to give the highest care, the highest person-centered care possible to everybody without forcing people to travel to these academic centers?

Dr. Subramanian: So there's been a few comments here. I just want to take a minute to read them, Benzi. "Unfortunately, palliative care is usually associated with end-of-life" is one that Ken brings up. Hedy says, "Most hospitals at present have a computer system. Each one should devote a screen to Parkinson's disease in its particular needs"-- kind of like you were talking about maybe like a checklist-- "both the ER and the units." Something about Monson Community Hospital where she lives in Traverse is trying to implement such a system, and I think that speaks to the electronic medical records and possibly having ways to have triggers to ask questions. And then Sylvia asks, "At what point in the Parkinson's disease process would you suggest the patient to be on a palliative care program?" Maybe you could just address a couple of those

Dr. Kluger: Yeah, absolutely. For Kent's point, absolutely. This is one of the biggest barriers I think with both patients but more so with physicians, is this idea that palliative care-- the right time is end-of-life and we really need to break that association. One of the things that we found actually in our research and maybe some people on this call me resonate with it is that the time of diagnosis is actually a time where there are a lot of palliative care needs. People are confused, they're grieving, there's a lot of changes in their life, they need help with planning. So we really need to think about palliative care as something that's proactive. When I give talks about this, I'll sometimes show a slide which is a Calvin and Hobbes cartoon in which Calvin is waiting for inspiration to do his homework, and Hobbes asks him, how will you know when you're inspired? And his answer is last-minute panic. That's kind of our current system of

palliative care, is that we don't do anything, and then at the last minute we try to do everything. That's not a great way to do palliative care. We can't un-burn out a caregiver after they've burned out. We can't turn back the clocks and allow people to spend the last three months of their life at home rather than coming in and out of the hospital. We really need to reinforce that message that palliative care starts at diagnosis; palliative care doesn't start two days before someone's about to die. I think Hedy's comment is awesome. It really reinforces the power that patients can have as advocates. I think we had a similar thing at the University of Colorado, where there was a problem that Parkinson's patients weren't getting their medications on time in the hospital. This is something where I think patients can really push the hospital and push doctors to try to change their systems to make things systemic. I think one of the things we learned from our studies is that we need checklists. When we started our study, I was a typical arrogant physician and felt like everyone else in the study needed a checklist, but I didn't. I would say within a few weeks of being in the study, I was really glad to have a checklist because it meant that I didn't miss things. We want all these things to be systematic. This is something that caregivers and patients can absolutely advocate for. I would say, at what point in Parkinson's disease would people be on palliative care-- this is something I've actually been thinking a lot about. We kind of have to also get outside of this mindset that palliative care is not like penicillin. It's not like palliative care is just this thing or like a big and loud program or something that it's one-size-fits-all. Palliative care is an approach to meeting the needs of the person in front of us, so palliative care is going to look different depending on where you are on your journey, but I think at every point of the journey, having a palliative care approach can be helpful. That's different than saying that you have to see a palliative care clinic. This is part of our educational work, is trying to help physicians and support groups and social workers and chaplains use the palliative care approach to help people no matter where they are in their journey. There may be a time if people have a lot of complex symptoms, if they're nearing the end of life, where seeing a palliative care clinic makes sense. But certainly at the time of diagnosis, if your doctor can do a good job with providing your diagnosis with compassion, if they can talk to you about the future, if they can connect you to support groups, you don't need a special palliative care team. The idea is that not everyone needs a palliative care team at every visit, but that everybody needs a palliative care approach. It's really kind of a paradigm shift in changing the way that we think about Parkinson's more than it is a clinic that everybody needs to go to.

Dr. Subramanian: Yeah, we can address these. Just to sort of understand a little better, I think one of the problems is that palliative care has been so connected with the word hospice and end-of-life that it becomes this continuum that everybody thinks is this last-ditch effort when there's no other treatments. Suddenly we switch the teams, and everybody hands off to this other team, and it's really not that. It's sort of this approach that should be educated through health care training for all healthcare providers, this more holistic approach to not just the disease, but the person in the framework in which they're living and the complete person, not just their physical but mental, spiritual, and all these things. This approach is important to revisit through different points from diagnosis in visits throughout and may become more intense at certain times, maybe when there's a crisis or a non-motor issue that comes up. And as the team gets to know one another, and as things progress, hospice is a very different role, which is the last six months or year of life. I think Farah just described that a little bit, and Dr. Katz-- Maya-- has also spoken about some of these approaches as she's seen them, so I think that's very helpful. Benzi, I want to give you some time to talk about fatigue because I think that's really something that you've done, has been an interest of yours, it sounds like even through this the squat that you were doing and kung-fu class or whatever. So maybe you can tell us a little bit about fatigue as you define it. Maybe tell us a little bit about approaches to helping it, not just from the standard playbook that we all get taught in Western medicine, but maybe even some of the thoughts that you have as a more spiritual and well-rounded person living on our planet.

Dr. Kluger: Sure, yeah so fatigue is, as I said, one of my early interests, and it continues to be an interest for me. About three years ago now the Parkinson's Foundation held an international working group, which I was a part of, and one of the things that came out of that-- which is something that you could look up-- is a definition of Parkinson's disease-related fatigue. Part of the reason why we wanted that definition out there is that people don't recognize how big a problem fatigue is for somebody with Parkinson's. Fatigue kind of falls under this invisible symptom. People can't see it like they can see your tremor, and it's very misunderstood. We actually just finished a study-- which is under review-- where we talk to people with fatigue, and one of their number one requests was for people around them to understand that fatigue really wasn't their fault. I think there's this idea that when people have fatigue it's because they're lazy or they're not able to tough it through or it's a sleep problem or it's depression, but fatigue and Parkinson's is something totally different. People I've talked to who have fatigue with Parkinson's that-- everyone's had fatigue at some point in their life-- but fatigue with Parkinson's is kind of more like you have a really bad flu. When you have the flu, you can take a nap, you wake up from the nap, you don't feel tired or sleepy, but you still don't have energy to do the things that you need to do. That's more what Parkinson's fatigue is like. Parkinson's fatigue can interfere with doing things day to day. It can make it difficult to do exercise, or if you do exercise then you have to pay the price for being in bed for three days, so Parkinson's fatigue is a big deal. It's actually the number one symptom that leads to disability claims in Parkinson's disease is fatigue. So I really want to make sure that we have it on the map. There are some common causes of fatigue that we want to make sure that we don't miss. There are sometimes secondary causes of fatigue. One of those can be medications. Some medications can cause sleepiness or fatigue. That includes both Parkinson's medication, some blood pressure medications. Dehydration or low blood pressure can cause fatigue. Vitamin deficiencies like vitamin B12 or vitamin D, low testosterone or low thyroid hormone, anemia, sleep apnea even though it usually causes sleepiness-- can be associated with fatigue. Getting a sleep study-- those are places that I would often start to make sure that we're not missing another cause of fatigue. When I talk to people about fatigue, I like to understand when it comes up and what the pattern of it is. For some people, the biggest part of fatigue has to do with concentration and mental fatigue. For some of those people, using a stimulant-- a medication like methylphenidate or Ritalin, the same medicine we use for ADHD-- can sometimes help quite a bit. That's one trick that I will sometimes use. Power naps is something that can be helpful for some people. There's going to be natural rises and lulls in energy, and you can plan your day around that. A lot of times, right after lunch is a great time for a power nap, and then you can get up from your power nap-- I would say no more than thirty to sixty minutes-- and get on with your day. One of our things of research that we found patients say and I think is useful and may be worth looking into is sometimes a small snack can help with fatigue. Sometimes doing activities that are meaningful can actually help with fatigue. We found that certain people, if they were feeling fatigued, if they could get into some music, get into a piece of art, or exercise-- something that was really meaningful to them-- that they could push through their fatigue. That's not true for everybody. I think one of the things that's also clear from our research-- and we're also working on another paper on this-- is that everybody with fatigue is not the same. For some people, exercise helps their fatigue. For others, it hurts it. One of the things that we're trying to also look into is trying to distinguish different kinds of fatigue. The idea is that I think some people with fatigue, it may really be driven by a sleep problem. Some it may be associated with depression. And for some people-- particularly younger people with fatigue-- we think that it's kind of its own disorder, and we're doing research. We actually just published a paper showing that in those patients, that fatigue seems to affect different parts of the brain than people with depression or sleep problems, and so I think there's a lot more work that needs to be done. That's actually a big area of advocacy for me right now. If we think about things like depression or pain-- which are also subjective symptoms-- because of the science that's been done, we now have a lot of

tools to treat those symptoms, but as of yet, fatigue is still something that has a lot of stigma around it, and so again I think we have to work to get the science more solid and also to reinforce this with physicians that fatigue actually is a serious problem and that we need better tools to treat it. As Indu hinted at, we did do one study of acupuncture which suggested that it could be helpful. There was a study in MS showing that mindfulness could be helpful. There's various other energy management strategies. Strength training actually seems to be potentially more helpful than other types of exercise. I think there's a lot of tools that we can work with, but again there haven't been enough studies right now that anyone has really a complete toolset. Dr. Subramanian: Okay, that's helpful. So let's talk a little bit about that acupuncture study. I also want you to tell me a little bit about-- as we'll get into with the acupuncture study-- placebo effects. Also, maybe you could define and in your own words a little bit about the nonspecific effects that you mentioned in that explanation.

Dr. Kluger: Yeah, so the study that Indu's mentioning was a study that we did with the Michael J Fox foundation grant. We randomized people who had Parkinson's disease and moderate to severe fatigue-- so fatigue that was severe enough that it was interfering with their day-to-day life-- to either get real acupuncture or placebo sham acupuncture. The way we did the sham acupuncture-- and if people have had acupuncture before, they'll know what I'm talking about-- before I got acupuncture, I was afraid of it because I don't like getting poked with needles, and I thought it was going to be painful, like getting a bunch of shots. But the needles in acupuncture are really very fine, and so it feels really more like just a pinch at the skin. So the way we did our sham was we used a sharp toothpick-- the patient was blindfolded-- and we used a sharp toothpick and we poked away from the real acupuncture points. People did not know what group they were in, so we did a good job of blinding. Also at the end of acupuncture we again kind of poked people and took out the fake needle and threw it in a sharps bin so people would hear that, so we did actually a really good job with our sham. What we found at the end of the day was two things. One was that acupuncture help people with fatigue, and about half of the people who took part in the study-- including people who had tried Ritalin and other medications and whatnot-- felt their fatigue was significantly better. The other important finding was that it didn't matter whether it was real acupuncture or the sham, and so it got us to thinking that sham acupuncture is more than nothing. People in the sham acupuncture group were having to go in twice a week. They were focused on their body. They had this intention to get over their fatigue. When I started the study, I actually had kind of a naive idea that if people in the placebo group got better, that we would just tell them that they got placebo and their fatigue would go away, and that's not what happened. People in the placebo group actually had to go back and see a real acupuncturist in order to maintain those benefits. So the placebo effect and these nonspecific effects are interesting. One of the things I think it suggests is that our unconscious mind has a lot more power than we typically give it credit to. There have been some very interesting studies of placebo with Parkinson's showing that with placebo-- so giving people a placebo Sinemet or placebo DBS-- that people can increase dopamine in the brain up to 40 to 60 percent. There's an enormous amount of power there, but it's a power that we can't tap into directly, at least not typically. It's got me very interested. I'd love to do a study on mindfulness. I would love to do some other studies to see if there are ways that people can learn how to tap into that potential more directly. Exercise is certainly one way that people can do it, but the placebo effect is not as straightforward as people think. It's not just expectation. You can tell somebody you're giving them a placebo, and they still get a placebo effect. It's definitely a pretty complex area and one where people are actually doing I think some very interesting research. It's again an area where I think there's huge untapped therapeutic potential.

Dr. Subramanian: Absolutely. There's a question or two about defining fatigue and diagnosing it. Could you tell us a little bit about how you're measuring it, what actually was the definition that you ended up-- you said something about like a flu kind of the feeling that you get-- but is there

more of a layman's definition or a scientific definition that you guys use in this paper and the study?

Dr. Kluger: Yeah there absolutely is. One of the analogies I'll use is the difference between being sad and depression. All of us feel sad from time to time, but clinical depression-- depression where you're down for two weeks and you can't get out of it-- is very different. I think one of the things about fatigue that makes it difficult is that we use the same word fatigue to mean a lot of different things. We use fatigue to mean tired, we use fatigue to mean how we feel after we work out, and we also use the same word fatigue to mean somebody with Parkinson's disease who can't do what they used to be able to do because of this fatigue. So the way we defined it was: number one, for somebody to have Parkinson's disease-related fatigue they had to have fatigue that was so severe that it was interfering with their ability to do day-to-day activities, so that's one part of the definition. The second part is to make sure that we're clear about what we mean by fatigue. We don't mean depression; we don't mean sleepiness. We mean a lack of energy or a lack of ability to get ourselves to do things, and that's also different than apathy, so with apathy people don't have motivation. With fatigue people have the motivation, they just don't have the energy to do it. So that's what we mean by fatigue. It's important that we distinguish it from depression or sleepiness or apathy because those are different things that have different treatments. I think those are the two big components in a nutshell, is that it's a problem with energy that interferes with your day-to-day life and that it's not depression fatigue or any of these other secondary things like low testosterone or low b12 or low blood pressure that would be potentially treatable.

Dr. Subramanian: Okay that's helpful. I think there's been in the chat some resources put up, and we'll link those, including your statement about fatigue with the Parkinson Foundation and some of these approaches. One question is that of the checklist-- harkening back to the checklist about the things to check in with around the palliative care-- symptoms-- I mean approaches-- and also the non-motor symptoms, and even the advanced care planning piece and checklists to help guide patients to trigger their doctor to handle these. Is there a central place or a resource that you know of that could help with this? And if so maybe you could give us some resources verbally now and then we can link them as well.

Dr. Kluger: So there are a few resources out there that are great for advanced care planning. One of those is called PREPAREforYourCare.org. One is the Conversation Project. One is called Go Wish. Those are excellent. As far as the checklist goes for symptoms and for some of the other things specific for Parkinson's Disease, that does not exist yet. If people wanted to-- both in the JAMA paper which Indu can send a link about, and in some other papers I wrote-- I actually wrote an implementation of palliative care paper-- there are checklists for what the physician and the social worker and other people are supposed to do, and you could extrapolate from those checklists to make your own checklist. One of the things that I don't know if Indu's talked about this or has plans to talk about it, but I think it may be worthwhile to think about kind of having a checklist for doctor's visits and how do you get the most out of your visit. There are out there-- and again I'm not the biggest expert on this-- there are what are called QPLs, or question prompt lists, that are out there that are made to help patients make their doctors better doctors. Again, as far as I know I don't think anyone's done this specifically for Parkinson's disease, but somebody should. Your question definitely reinforces to me-- actually as me and Indu work as for the Neuropalliative Care Society-- I think one of the things that our website could provide would be checklists for patients to get more out of their neurology visits and checklist for patients to be able to make their doctors take on a palliative care approach even if they didn't have that on their agenda. As an activated patient, you bring the agenda, and you get your doctor to do a better job than they might have done without you being so active and engaged.

Dr. Subramanian: Yeah absolutely. I think those are unmet needs, and this is sort of why we're talking to patients and to find out what your needs are and how we can try to help meet them.

So the fancy fingers of the PMD Alliance have put the Go Wish, Prepare for Your Care, the Conversation Project links. Somebody also mentioned the Five Wishes, and the Davis Phinney Foundation apparently does have some checklists, but I think this should be revisited, and I'm happy to help work on that with you Benzi. I mean not just in Parkinson's, probably there is a need in many other diseases in neurology as well. I want to spend-- oh go ahead.

Dr. Kluger: Just one other thing, if I could-- another link if we could provide it. Kirk Hall--I don't know if you ever had on the show, but he has a great blog. He actually has two children's books about Grandpa Shaky Paws. He published a journal in NPJ Parkinson's disease on a patient's perspective on palliative care. I think he has checklists in that article, and that article is also free and open access, so maybe we could also provide a link to that one.

Dr. Subramanian: Yeah, I think by starting the links and seeing what we have already maybe we can see what's needing to be done. I think that's great. Well Benzi, I think we have about 13 minutes or so to share some more wisdom of yours. I wanted to give you a space now to talk a little bit about joy and the concept of positive medicine because I am really all about silver linings and positive perspectives and trying to find joy and purpose has been something that I've really been speaking more about in my definition of health to patients. So I want to hear your concepts and a little bit of your ideas.

Dr. Kluger: Yeah, thanks for asking that question. My journey in palliative care has had all kinds of wonderful surprises. One of them has absolutely been joy. It actually I think came up for the first time in kind of a surprising context. We had a woman that we were taking care of who had corticobasal degeneration. In Colorado where I was working at the time, we had medical aid and dying, and she made a request for medical aid and dying. Our chaplain, just to explore that and to understand where her suffering was coming from, asked her if there were things that she still enjoyed, and she said being around family. Then he asked her, "well how much more time would you like to spend with family?" And her eyes lit up as if he was an idiot and said, "A lot more time, you fool." What we realized is she actually changed her mind and ended up deciding that she wanted to do hospice at that time rather than medical aid and dying. It was just this very empowering moment I think for our team to hear that we really should be spending a lot more time than we are looking for opportunities for joy. Since that time, we purposely have this on our checklist absolutely-- in addition to looking at sources of suffering, we look for opportunities for joy. That's looked for some people-- actually there's a woman I remember with quadriplegia who we got skydiving because I was important to her. We've had RVs modified so that people can continue to travel. Sometimes it's simple things like encouraging people to eat more of their favorite food, encouraging people to listen to more of their favorite music, to catch a sunrise, to hold hands, to tell stories with their loved ones, but there's really this kind of untapped potential out there. I think kind of ironically with COVID, I think one of the silver linings has been that people are really recognizing the importance of joy in their lives. The New York Times has a new series about joy. Actually, with burnout in medicine, there's been a lot more attention paid to joy. Joy kind of becomes the secret weapon that we can use when we have an incurable illness. I can't cure your Parkinson's disease, but what we could hopefully do together is, if you have a year or two years or five years, we can really work hard to make that the most meaningful and the most joyful and loving and connected time of your life. We can try to get a family reunion. There is actually a great article in The New York Times and also in journal-- I think was in [palliative?] symptom management-- that had people asking patients about what's on their bucket list, and using that question as a way to prioritize the care we provide because if your bucket list includes going to Ireland or going to Australia or skydiving or whatever there's no better time than the present to do that. If you have a progressive disease, there's no better time than the present. It may bring up things that may not be possible, but maybe we could modify them to make them more possible. Maybe you can't hike a fourteener, but we could spend more time in the mountains, or you can spend time sitting in front of your favorite lake in nature or other things. So yeah, so it really got me thinking. That's really I think become

incorporated into our philosophy for both patients and family, is to not only focus on suffering-- and suffering is important, and I don't want to whitewash it or make it sound like suffering doesn't have grief and suffering doesn't happen with Parkinson's because it does, and we need to acknowledge that, we can't ignore it. But suffering and joy can coexist, and joy can make suffering easier to bear. So I think it's really important that we consciously and intentionally bring joy into the conversation.

Dr. Subramanian: Absolutely. I know Benzi you've spent a lot of time talking about caregivers as well and a lot of your focus has been on them and how important it is and we've talked about that. Could you in the last maybe few minutes-- and I'm going to give you a few minutes of just inspiration and closure as well-- just spend a little time telling us your pearls, maybe towards approaches for caregivers? There are a number of caregivers on the call as well, so if you could just tell us a little bit about your thoughts on that.

Dr. Kluger: Yeah so for caregivers-- or often times I like the term care partners, that we're kind of partners in doing these things together-- a few things to think about. One again, with the positive side is thinking about-- and this is true for patients-- how do you want to grow through this illness? Are there opportunities for you to grow? Are there ways that you can find meaning along this journey? Are there places where you can find joy along this journey? Are there places where you can find grace or spiritual growth? I think those are really important questions to ask and can be empowering because a lot of times if you're a care partner, I mean you certainly didn't sign up for. This wasn't the plan, even though you might have said until death do us part, in sickness and health, but not this kind of sickness. We didn't sign up for this, but we still have opportunities here. Second, I think is to reach out for help. This is not a sprint, it's a marathon. If you burn out, everything's going to fall apart. It's really important that you make time and effort for your self-care. That could be taking a few hours a week to do something that's meaningful to you, to just take a vacation from your life, to sit by a lake, to have a therapist, to talk to friends-- but really important that you find ways that you can recharge. Nobody wants or expects you to be perfect or selfless. One of the things is actually a source of joy for me is seeing how friends, neighbors, families will come out of the woodworks to help you if you just ask. I think a lot of times we have this mindset, particularly in America, where everyone's supposed to be so damn independent that nobody wants to help, but people are dying to help. It's amazing to me, I mean it's lovely to me to hear about how neighborhoods and families and others have come together to help caregivers when they just asked. I think part of that-- which is a difficult thing-- is kind of finding this practice of grace and acceptance. Being able to accept help can be as big of a gift-- sometimes even more so-- than giving help. Being able to accept help and being able to do so gracefully really helps this other person. It's not even a matter of putting our pride aside. It's just developing a different kind of grace when we approach that.

Dr. Subramanian: Absolutely. I think so much of what we have talked about sometimes, when I talk to caregivers, they feel guilty about taking pleasure and joy in things. There's tremendous guilt about needing to be in the moment of suffering at all times. There's a way to be present but not take all of that and then breathe and live that all day long. It's important for you to recharge, and we rebuild and share these beautiful things that life has to offer with gratitude and grace and joy. I mean these are words that-- our emotions that-- are so important along with these sort of guilt and sadness and anger and all the other things. I think sometimes just pausing to identify the mix of emotions that one can have-- and we've been doing some of this with COVID-- just sort of sitting even with our students or our trainees and saying, "how are you feeling?" Sometimes it's positive emotions mixed in with negative emotions and just being able to understand all of what we're processing is tremendously helpful. I think our caregivers just to hear that sort of self-care and I know, Benzi, you and I have been talking even as healthcare providers about taking time for ourselves, to care for ourselves even. And it is hard when we give so much to just protect and take care of some time for ourselves, and I think this is something that you and I have just been trying to drizzle in in our own lives. I think being

cheerleaders for our patients and our care partners to do the same is just so important. It's not something to feel guilty or self-indulgent, it's really just to take care of yourself so you can take care of our lovely patients. I think that's absolutely important. A few questions. Everyone's been very positive about this so far. [Marissa?]: Seems like we should start meetings by asking, what puts a smile on your face? Then encouraging folks to continue to add the activities that provide the happiness. I mean I think this COVID time frame-- and I'll give you a minute to speak on maybe the silver linings that you're seeing of that-- is giving us a minute to pause to really sort of reflect on the things that are important, that bring us joy and meaning and to connect with people that are absolutely important to us, as you were mentioning. So tell me a little bit about what you're taking away from this COVID time frame and some silver linings and sort of some hope, maybe a message or two of hope for the future as well for our patients and carers out there.

Dr. Kluger: Yeah it's so there've been a few kind of unexpected things that have happened with COVID. One is, I think it really in a lot of ways across society has kind of opened our eyes to what's possible. For years telemedicine has been possible, and there's been various things of red tape and whatnot that have gotten in the way and then COVID happens, and all of a sudden we're doing telemedicine. I think that that in and of itself is great, that that's moving the needle forward, and it's allowing us to provide care in the home and provide care in creative new ways that we hadn't before. Another silver lining that's come out of this-- which is again maybe surprising, it doesn't get as much attention on the news-- is that palliative care has really gotten a huge boost through COVID. We hear all about frontline workers and ventilators and ER physicians, but palliative care physicians have been essential during the COVID epidemic, pandemic, right from the get-go. The ICU doctors were needing help: how do we help people who are dying of COVID? How do we help their families who may not be able to be present there? How do we keep people out of the hospital? How do we help address some of the worries that people have about going to the hospital? As I've been doing care for people, I know COVID has put a lot of strain on both patients and caregivers, and I think has increased our need as a healthcare organization to provide better caregiver support because a lot of the typical ways that we supported caregivers like adult day care and family and friends visiting are no longer present. I think in some ways COVID is kind of accelerating a lot of the change that I was hoping to happen over time. This is not the way that I would have wanted it to play out. Nonetheless, as one of my mentors said, never waste a crisis, so we'll take advantage of it and we'll continue to push forward.

Dr. Subramanian: That's great. Well thank you so much Benzi. This has been so amazing to have you on. I wanted to have you on for a while. You're just an inspiration in so many ways, not just with your logical thought process of how to approach things, but you're really trying to change things from I think the foundation-- so doing the research painstakingly, writing the grants to get this type of research done, but also in your day-to-day inspiration from an educational perspective as a mentor and leader in this field, and also as somebody who as a friend and a patient advocate that I can really reach out to you and say how can we approach this differently, and you always have a sense of how to get things done in a sort of a very holistic and beautiful way. I really appreciate that. There's been a few comments here. From Joanne, I'll just read this last one, and then we'll hand it back to the PMD gang. "I can fully appreciate and want to thank both you and Benzi on the comments made on positivity and silver lining recognition. Thank you for that." I think patients are really looking to have some acknowledgement of many of these things that they've been thinking and also some hope and joy that we can bring to them as well, so I really appreciate that. Handing it back to you guys at PMD Alliance for our goodbye wave and any other sort of notes on our future. We have some really amazing speakers-- Ray Chaudhuri joining us from the UK, we have speakers from Australia, and on Friday with Simon Lewis, so really try to join us. We've put out the call for speakers, and no one's turned me down yet, so I'm just so excited because I think this is such a

meaningful group. I think we'll share the videos on YouTube as well, and we'll continue to build the momentum for positivity and change.

Anisa Mitchell: Well thank you very much Dr. Kluger and Dr. Subramanian. Thank you everyone for joining us today. There's a lot of fantastic nuggets in today's session. We look forward to seeing you at our next ones coming up, and let's do our wave goodbye everybody. See you! Thanks for joining.

Dr. Kluger: Thank you!

Dr. Subramanian: Thanks!