

Dr. Swathi Kiran - Overcoming Aphasia: New App Improves Access To Therapy

Dr. Swathi Kiran is the Founding Director Of The Centre for Brain Recovery and her research has enabled the development of the constant therapy Aphasia Recovery App.

Rewiring The Brain with Michael Merzenich

Survival Chances After Stroke with Patrik Hutzler

Constant Therapy Website

Center For Brain Recovery

Constant Therapy Signup

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Neuroplasticity after a stroke is a thing. And this myth that there is a plateau after which your brain cannot recover is a myth, it's completely false. The brain can recover, and reorganize function with repeated practice. The scientific community is completely convinced that Neuroplasticity is a thing. What we have not yet fully convinced are the neurologists and the funders, the payers.

Intro 0:36

This is the Recovery after Stroke podcast. With Bill Gasiamis, helping you

navigate recovery after stroke.

Bill Gasiamis 0:49

Hello once again and welcome to the Recovery after Stroke podcast. If you are a stroke survivor with a story to share about your stroke experience, come and join me on the show. The interviews are not scripted, you do not have to plan for them. All you need to do to qualify is be a stroke survivor who wants to share your story in the hope that it will help somebody else who's going through something similar.

Bill Gasiamis 1:11

If you are a researcher who wants to share the findings of a recent study, or you are looking to recruit people into studies, you may also wish to reach out and be a guest on my show. If you have a commercial product that you would like to promote that is related to supporting stroke survivors to recover.

Bill Gasiamis 1:30

There is also a path for you to join me on a sponsored episode of the show. Just go to recoveryafterstroke.com/contact and fill out the contact form, explaining briefly which category you belong to. And I will respond with more details about how we can connect via Zoom.

Introduction - Dr. Kiran Swathi



Bill Gasiamis 1:50

Now this is episode 269. My guest today is Dr. Swathi Kiran, who is the founding

director of the Center for Brain Recovery, where the focus is to detect and identify neurological disorders early, understand the mechanisms underlying the disease, evaluate which treatments work for which patients, and enable success in the real world.

Bill Gasiamis 2:15

Dr. Swathi Kiran welcome to the podcast.

Dr. Swathi Kiran 2:19

Hi, there, Bill.

Bill Gasiamis 2:21

It's really lovely to have you here. Because one of the things that I do that some people don't know, that I do is every once in a while, I get together with a group of stroke survivors who have aphasia. As somebody who's a stroke survivor who doesn't have aphasia, it's still very difficult and complicated for me to understand how to support people like that and to understand the complex nature of the condition.

Dr. Swathi Kiran's background

Bill Gasiamis 2:56

And it seems like it's a really difficult and challenging condition, and probably one of the most challenging conditions because if I'm considering it from my perspective, not being able to have my voice, or the fluidity of my voice, I think would be quite the challenge that I would seriously want to overcome. Tell me a little bit about your background, how you got to be in the role that you're in, and what your current role is.

Dr. Swathi Kiran 3:32

Bill, my current title is The James and Cecilia Yang professor of neurorehabilitation. I'm also the founding director of the Center for Brain Recovery. So I think both my titles, explain what I do, I study brain recovery, and I'm specifically focused on neurorehabilitation.

Dr. Swathi Kiran 3:59

I've been doing this work for the last 25 years or more. And my main goal is to harness what we know about Neuroplasticity, especially after somebody has a

stroke. And my area of focus, as you pointed out is to study people who have had a stroke in the left hemisphere, which is the part of the brain that is involved. In language processing. Sometimes you have a stroke in the right hemisphere, but most of the people I work with have had a stroke in the left hemisphere and they end up having aphasia.

Dr. Swathi Kiran 4:39

So over the last 25 years, I've spent most of my research work focused on understanding whether we can help people who've had a stroke and how well we can capitalize on that both by understanding Neuroplasticity and using data science and machine learning more recently.

Bill Gasiamis 5:03

okay, I just remembered something, my niece is currently studying at Uni, and she's just decided to go into speech therapy, she's going to focus her work, on speech therapy. And I said to her, Renee, you know how some people have aphasia? Who can't speak properly, but they can sing? Why can they sing? But they can't speak properly? Why can't we use the singing part of the brain to switch on the talking part of the brain or to transfer Neuroplasticity to that part of the brain?

Bill Gasiamis 5:40

And she came up with an answer, which was that it's a completely different part of the brain, and it's on a different side of the brain or some different location from the speech center. And then that is where the difficulty lies, where the challenge is to sort of bridge that gap and convert one part of the brain to a different function or an added function. Is that familiar? Tell me a little bit about that.

Dr. Swathi Kiran 6:10

Well, your build your niece is a very smart person, she, I think, has already learned what is I think the most important thing in terms of the anatomy and the neurophysiology of what the brain can and cannot do as a function of recovery. So she's right in that the part of the brain that is processing language, like when we're speaking and coming up with words is in the left hemisphere of the brain. And oftentimes rhythm and melody, and, and music are in other parts of the brain, sometimes the right hemisphere up, but not we don't know exactly where.

Dr. Swathi Kiran 6:51

Because of this stroke in the left hemisphere, the connections from the left hemisphere, and damaged parts of the other parts of the brain are disrupted. And that's exactly what your niece also explained correctly that part of Neuroplasticity is rebuilding the connections. But you don't always get to rebuild connections because you don't get new neurons to fix the problem. You just have to re you have to do with whatever is left. And in that process. Real Neuroplasticity is limited by the existing connections in the brain. So while singing can help, or melody and tune can help speech production, it depends on what the damage is and how those connections can be rebuilt.

Bill Gasiamis 7:44

In Episode 108, I interviewed Dr. Micheal Merzenich. Who, in the field of Neuroplasticity, I, I asked him once you know, you're considered to be the godfather of Neuroplasticity, he kind of took that a little bit, you know, oh, well, you know, not other people came before me. And they did. And that's true. And that's cool. But he led an amazing team of researchers in the 90s that created the first cochlear implant, and created a whole bunch of work around proving the possibility of sensory substitution, or I think that's the word where they substitute.

Bill Gasiamis 8:27

For example, the back of the head and the way that they enter the back of the head with a device to send sound to another part of the ears of Ariana another water the part that creates hearing through a different mechanism rather than the eardrum, the ear canal, right. And, when I spoke to him, I specifically asked him about the difficulty of working in that space, when, for hundreds of years, Neuroplasticity wasn't proven to be a thing. And it was kind of almost frowned upon.

Bill Gasiamis 9:05

And stroke survivors were told, Well, this thing that you have now now that you're here, you're probably not gonna get any better, you're probably not going to walk again. And we still hear that today. There are so many stroke survivors who will get the response from the doctors, or you probably won't walk again or talk again or do all these things again, only to motivate a lot of stroke survivors to prove them wrong, but some actually, potentially to do what the doctor suggested.

Bill Gasiamis 9:34

When you started your work 25 years ago, how did you deal with the space of the new resurgence of Neuroplasticity and the early stage at which was being used and potentially not accepted? As it is accepted now, how did you deal with that as a person working with Aphasia?

Dr. Swathi Kiran 10:03

That's an excellent question. As, a very young researcher in this field, I read all of my papers about Neuroplasticity. And it essentially guided the kinds of thinking that I and many other researchers in my space have been trained to think which is different, as you pointed out, I want to say that you've answered everything I was going to say was already in your question, but I'll phrase it differently. Most. Most people were trained to think that Neuroplasticity does not happen in adult life. And some of the early work that you were referring to in the 90s.

Dr. Swathi Kiran 10:45

It sort of made us all think, Wait a second, there is a way for the adult brain to gain some of that Neuroplasticity. And, and every one of us who worked with stroke survivors knew that they were getting better, they were recovering over time. So they have to be Neuroplasticity in the brain. But as you correctly pointed out, I want I think I've spent the last 20 to 25 years convincing people, researchers, clinicians, doctors, and patients, that Neuroplasticity after a stroke is a thing. And there's this myth that there is a plateau after which your brain cannot recover it is a myth.

Dr. Swathi Kiran 11:32

It's completely false. The brain can recover, and reorganize function with repeated practice, with repeated stimulation and therapy. That's, that's what those early studies showed it was about you practice something your brain cells, your neurons learn to read, no, they keep firing, and they reorganize it they collect together. And that's exactly what happens after a stroke as well. I would say that today, the progress we've made so far as the scientific community is completely convinced that Neuroplasticity is a thing because we have several tools at our disposal.

Dr. Swathi Kiran 12:13

Disposal, like new brain imaging, shows that somebody who has had a stroke for 15 years, like yourself you've had a stroke for a while, but somebody who's had a

stroke, can continue to show changes and improvements in their brain. What we have not yet fully convinced are the entire the neurologist, and the funders, payers, because I think that is when we would have fun, convinced everybody because I don't think I don't think we have to I don't think I have ever convinced a stroke survivor, they know they can recover over time.

Intro 12:52

If you've had a stroke, and you're in recovery, you'll know what a scary and confusing time it can be, you're likely to have a lot of questions going through your mind. How long will it take to recover? Will I recover? What things should I avoid? In case I make matters worse, doctors will explain things. But, if you've never had a stroke before, you probably don't know what questions to ask. If this is you, you may be missing out on doing things that could help speed up your recovery.

Intro 13:22

If you're finding yourself in that situation, stop worrying, and head to recoveryafterstroke.com where you can download a guide that will help you. It's called seven questions to ask your doctor about your stroke. These seven questions are the ones Bill wished he'd asked when he was recovering from a stroke, they'll not only help you better understand your condition, but they'll also help you take a more active role in your recovery, head to the website now, recoveryafterstroke.com and download the guide. It's free.

Dr. Swathi Kiran 13:55

So it's pushing the pushing the work over and over again. Until we can convince payers that even for someone who is 10-15 years after a stroke, they have the potential to recover and they should receive the therapy that's still work that needs to be done.

Neuroplasticity and stroke recovery with researchers



Bill Gasiamis 14:14

Yeah, thank you for saying that. You know what because a couple of episodes ago, episode 266 I was interviewed by a gentleman who has an organization here in Australia called, called Intensive Care at Home. And what he's done is push to have people come out of the intensive care ward and transfer the intensive care service to their home where the family is. It solves so many problems but in the beginning of his creation of this intensive care at-home business.

Bill Gasiamis 14:51

He provides intensive care nurses for the patients, whether they are stroke survivors or not No matter how the gentleman's name is Patrick Hutsul, Patrick related, the situation where, they bring people home and care for them and take away the burden of that hospital bed being taken up by a long term, intensive care patient.

Bill Gasiamis 15:22

And then they make it available for another intensive care patient. But what happens is he's constantly fighting with insurance companies, because they're talking about cutting the funding. After all, they use words like plateau, as a tool to stop the funding.

Bill Gasiamis 15:42

They use that as a word that now that you've reached here, there's nothing we can do for you. What we need to do is cut the funding you're on your own. Well, the reality is, I know and stroke survivors know that the plateau is when the funding should be doubled down on. And I'm not saying that it should be for everybody, I understand that money is not limitless. But it's when the most focus in rehabilitation needs to begin because the plateau is the sign that if we stop here, we might not progress any further from here.

Dr. Swathi Kiran 16:19

Yeah, you're, 4,000%, right? And I have made my life and career mission to essentially prove that point as much as I can to change the practice, at least in the US. It's very, very hard. But it is what I do in my research is to just keep making that point that there is no plateau, as you said, it's a word that people use to stop funding. So we just need to prove, and show more and more and more data to make that point.

Bill Gasiamis 16:53

Yeah, I love that. I love that there are people like you out there, fighting those battles. For us, it's so amazing that we are so supported, it doesn't show it feels lonely, every once in a while you kind of get to this point and go, Oh my gosh, this is so lonely. Nobody understands me, and I'm struggling with my new self by identity, all these things. And you feel like no one is in your corner sometimes. But the reality is so many researchers that are in our corner, you're a great example of that. And I'm just so grateful for that.

Bill Gasiamis 17:28

And I don't understand why people like you decide that that's what you're going to do for your career. But I know that my niece is that way inclined as well. She wants to go out that direction and support people that she's never met before. And help them overcome really difficult neurological conditions. And it's like, oh, my gosh, what a great thing. I'm very grateful for the headset, thank you.

Dr. Swathi Kiran 17:52

It is very gratifying. It's hard work because every time you think you have the burden to make the proof, the bar is higher, and then you have to reach that burden. But it is very gratifying. As in, you know, you're making a difference. I do think that at least in the US, as I said, the scientific community does believe that Neuroplasticity is a reality for people who have a stroke. And so not only have we spent the time publishing the work, you know, I do my work. I also work with the National Aphasia Association, I'm on their board, and we make sure everybody knows that information as well. It's about making sure that you do the work and then making people aware of the implications of that work.

Bill Gasiamis 18:41

Yeah. And then the next phase is applications. How do you guys work in that space? So you have the you create the concept, you work out what the

implications of that at? And then is there an applications phase? Do you guys get involved there?

Dr. Swathi Kiran 18:59

In terms of asking me a question more specifically, in terms of.

Bill Gasiamis 19:03

So how do you apply the findings from your learnings, for example, you come up with a concept, you put a whole bunch of research into it, you get some data, and then and then where does the data go? What do you do with the data?

Dr. Swathi Kiran 19:18

Yeah, so there are two ways we have been doing this, I'll give you the more practical application that that I think we've made a difference. And so early on, in my research, and, I would say over the last 15-20 years, it has become very apparent that one of the things that seem to matter for people to get better off to recover after a stroke is getting intensive, sustained repeated therapy, you can get casual occasional therapy that's not going to help you. And for someone like yourself, who's shown so much recovery, I'm sure you've seen that when you worked hard.

The Constant Therapy APP

Dr. Swathi Kiran 20:01

That's when you saw the gains. And so that scientific data is very clear that to get the brain, to fire and reorganize, you need lots and lots and lots of practice. So scientific data that is, is precise that the more you practice, the more the brain can reorganize. But the reality in Australia and the US is no patient is getting that much therapy, they're getting 10 sessions, 20 sessions of therapy, and then they're told to go home. And then what, what is the potential just basically reduces to almost nothing, because you're not getting the therapy?

Dr. Swathi Kiran 20:37

So because I knew that was happening, I co-founded a software company called Constant Therapy, which is an app you download. And you can practice therapy at home so that you can get therapy at home, on your phone, or your tablet, practicing the amount of repetition and, and sustained improvements that you need. So patients sit at home, they practice five times a week, 60 minutes a day.

And again, we've taken that data and published that data showing look, if you practice that much, you can show improvement.

Dr. Swathi Kiran 21:17

So that's a that's, that's something that's changed people's ability to change on their own to make their difference. And I'm very happy about that. Because finally, at least in the US people know about it. When patients get discharged from the hospital, the speech-language pathologist tells them, maybe you should practice this when you get home and they go home and they practice. So it's made a difference that way.

Bill Gasiamis 21:41

Yeah, that's excellent. So, Constant Therapy is the concept. It's what the organization's called. And what specifically does the app do? How do you use the app? Can you give us a bit of an understanding of that?

Dr. Swathi Kiran 21:57

So if you have trouble, if you have if you've had a stroke, and you have trouble understanding what people are speaking to you in terms of, you know, giving you instructions, or they're, they're telling you things, or you have trouble reading, the app is organized in terms of every domain, comprehension, reading, spelling. And after you download the app, you try things.

Dr. Swathi Kiran 22:26

You try, you sort of test yourself, but in the app, it tells you where your level is. So you have it says you don't have trouble with understanding, but you have trouble with reading, and it places you on a therapy regimen.

Dr. Swathi Kiran 22:39

And then it uses AI to give you therapy exercises every day and your practice. So if you have trouble understanding sentences, it'll you keep practicing on the app, it'll keep telling you sentences, and you have to show how you understand them. As you get better, the sentences get longer, then they become you know, passages as you get better, they become voicemail messages.

Dr. Swathi Kiran 23:04

So it takes you through the therapy, what you have to do is practice it in the app. It's it's very good at speech recognition. And you can speak to it and it will recognize what you're saying. Those are just examples.

Bill Gasiamis 23:19

So that's fantastic. Because 10 years ago, there was nothing available for people to take home after a stroke that they could use daily to help support their recovery. I remember Michael Merzenich had already back then brain HQ already set up and you could do the brain training games. And I did a fair bit of that. Brain HQ was it was kind of it was the thing that I needed because I could speak could communicate most of the time in my three years of my whole drama.

Bill Gasiamis 23:57

I was able to at least communicate, but cognitively it helped me to develop my my focus and my concentration, I think yeah. And, and it was awesome. But it was the only thing that was out there then. And I love this version of the stuff that you're doing because it's using AI and it's something that a stroke survivor has aphasia can do. And you know what's best about it is that don't have to travel if they're in an isolated location, or if they're in the middle of nowhere in Australia in the US, and they could just download it and do it all from home.

Dr. Swathi Kiran 24:43

Yeah, exactly. That's exactly why we developed it. And you know, what's been a full circle really, is that because we have so many people using the app, we're now able to take that data Back, analyze that with 1000s and 1000s of users, and then write the same papers that say, Look, this is the kind of practice you need with the hope of changing policy. So in my mind, as a researcher, this is coming full circle, because I need this kind of data to convince payers and funders that you have to change policy.

Bill Gasiamis 25:23

So it's much easier to also capture the data where in the past, you would have had hundreds of people trying to capture data over many, many years. And then by the time you capture it, 10 years have passed, a decade has passed, and you still haven't made any massive inroads, whereas now you can also as part of the recruitment process of somebody that's who has aphasia, to improve their condition. They're also providing relevant and important data.

Bill Gasiamis 25:24

Yeah, hundreds and 1000s of data points.

Bill Gasiamis 25:56

Yeah. Yeah, that's fantastic. It's so exciting. So I might have skipped around my conversation, it just flows out of my head the way that it comes. And when I get excited, it just goes all over the place. But tell me about some of the work that you're doing now. Who are you working with? Who are you collaborating with? Tell me a little bit about what's happening right now.

Dr. Swathi Kiran 26:21

Right. So, one of the answers I gave you earlier also was, I think I said, I have spent a lot of time convincing the scientific and clinical community that the brain can recover. And there is Neuroplasticity. So now I'm focused on trying to answer the question. Yes, we know there is Neuroplasticity. Yes, therapy helps people. But do we know which therapy is perfect for the right person? Can we predict for each person? What's the right therapy for you? Should you be going to an intensive program for six months, like a boot camp?

Predicting stroke recovery outcomes using AI and machine learning



Dr. Swathi Kiran 27:07

Or should you be going to club social club where you get practice? So that's what I'm focused on right now is helping you predict or prescribe which patient which therapies, are perfect for the right person. And again, that takes a lot of data. But as I said, some of the tools we have available to us are brain imaging tools. So we're able to see very, very sophisticated and clear pictures of the brain, What part of the brain is damaged? What part of the brain is intact? How are the connections? As you pointed out earlier, how are the connections intact?

Dr. Swathi Kiran 27:42

And how are they affected? How is the brain connectivity set up? So we're using

all that data about the brain to develop models to predict what would be the level of recovery someone's going to show so you know, just simple things like the more the damage a person's brain has, and the fewer connections that can make the less recovery, we will, we would probably show, but it's a bit more nuanced than that as well because we're able to use these machine learning models to make a precise guess, at how people can expect to recover. So that's, that's a prediction. It's a precision medicine prediction work.

Dr. Swathi Kiran 28:24

So that's one area of work that uses a lot of brain imaging data, which is hard to do. But we've been fortunate to get that data. The other, as I said, is to use AI and machine learning to take people's behavior and see if we can then also make better estimations of how much therapy somebody needs.

Dr. Swathi Kiran 28:24

What's the kind of dosage that somebody needs? Again, to come back to making policy decisions of don't waste somebody's time telling them that they can only get one day a week of therapy, it's never going to change their brain or they're not going to if they want to go back to work if they only receive one session of therapy every three weeks.

Dr. Swathi Kiran 29:07

It's a waste of resources and effort. So, we're trying to again, use machine learning and AI, there are two because we have data now, which we did not have 10 years ago, we didn't have the kind of data we have now to create these algorithms and predictors that say here's what to expect so so I would say the work that I'm doing right now is a lot about trying to predict the future for, for individual patients.

Bill Gasiamis 29:35

Okay, I like that peer into the hourglass into the glass into the glass ball and see what the future is gonna be. That's good because that offers hope. If you can predict a positive future, you might not be 100% certain that that's a positive future for that person, but if you can offer hope towards that they might prove you right. One of the interesting things is when you hear somebody gets one hour a week of speech therapy, it's almost like, the system is proving themselves correct in saying that funding this particular thing is not going to get results.

Bill Gasiamis 30:20

Because look at the data, we have people who have gone through the program, you know, they didn't get results, we shouldn't fund this, we should put our funding somewhere else it feels like the system previously, was all about proving that recovery is not possible is it wasn't about going, let's get excited about the possibility of recovery. It was all about. Yeah, we need to stop funding this because it's probably not going to happen.

Dr. Swathi Kiran 30:49

Right. But then I feel I mean, I've been doing this for a long time. And there have been many years where we thought is this even going to make a difference? But I feel optimistic. Now, for two reasons. I feel like were the optimistic phase of this, for two reasons. First of all, I and many other researchers, like myself in this field have access to a lot more data, sophisticated data, good data, and a lot of data. So we can make better conclusions about what's working and what's not working. That's one thing.

Dr. Swathi Kiran 31:26

The second thing, which I think is very important. And I'm curious to see if you have experienced this in Australia as well. But as you pointed out in the introduction, when you have a stroke, and you can't communicate, it's extremely difficult and very socially isolating. So most people who have had a stroke and have aphasia, stay home, don't get out, find themselves isolated, and are lonely and depressed.

Dr. Swathi Kiran 31:54

And until the pandemic, that was just the way those people lived. And only after the pandemic that people realize, if you stay home all the time, and don't talk to people and socialize, it can affect your mental health, and it can affect who you are.

Dr. Swathi Kiran 32:14

And so I feel like Finally, there's some acknowledgment of what it's like for someone to have a stroke and have trouble with communication and socialization, and why we need to do something about it. That's an awareness that happened, I would say in the last couple of years. And I'm very optimistic for that reason because I think now the world knows what people with Aphasia have faced all these years.

Bill Gasiamis 32:41

Yeah, it is. One thing that is well, as far as I'm concerned, if there's one thing that came out of that pandemic, is that awareness of the limitations of the way that we go about supporting stroke survivors, for example, it's all done on-site, it's all done in a hospital, it's all done under this particular situation. And now, we can't. So what have we done? Have we created a two-year setback for all stroke survivors who are recovering? And if we have? Well, we can't do that? Can we do it another way?

Stroke recovery and therapy access



Bill Gasiamis 33:23

And this is what I love about the fact that you've got constant therapy available and possible for people to use at home because, well, no, we're not limited by travel distance, lockdowns, whatever, I hope there's never another lockdown.

Bill Gasiamis 33:39

But in Melbourne, Australia, we had two years of lockdowns, and we were locked down for the majority of the time, I would say that, we would have been in some kind of a hard lockdown for at least 12 to 13 months. And then there's a whole bunch of soft lockdowns, but then accessing the medical system was impossible, you couldn't access any part of it for anything.

Bill Gasiamis 34:01

And, it felt like what we were doing was creating a situation where we're putting people setting people back. And from somebody who's naive, and doesn't understand anything about epidemiology and doesn't understand anything about diseases and all that kind of stuff. What I would have thought was, that you guys were trying to save one part. And this is not a political statement. I think you

could try to save one part of the community, which I get, and it's important, but what about my community?

Bill Gasiamis 34:31

The stroke survivors, you know, how do we help them get back to life after stroke and be people who are participating in the community and who are active and who are paying taxes and who are doing all the things that you guys need people to do so that we're not a complete burden on society, so to speak from a medical and cost perspective, right. So yeah, absolutely are what you're offering I hope that has never been before. And that's why, where, and that's why this podcast exists because I didn't have the hope that I needed.

Bill Gasiamis 35:11

When I was going through this 12 years ago, 10 years ago, nearly, I needed to find my I needed to create my system. Yeah, yeah, and hope. And I might be able to get this or I might be able to, you know, shrivel up in my home and just sort of forget about life. And that wasn't an option. So it's

Dr. Swathi Kiran 35:38

good for doing that. It's the hardest part that people have had to take us really, because it's not easy at all. And so you know, really kudos to you for doing this and showing the way for other people.

Bill Gasiamis 35:53

I think it was my survival plan, I had no choice, I had to do something, it was either that or just, you know, shrivel away, you know, it wasn't going to be a good outcome if I didn't go this other path. So I try and serve as an example of how people can move forward.

Bill Gasiamis 36:11

Even if they have more deficits than me or they're worse off than me in some way, we can still move forward. I wanted to ask you about therapists because the therapists that I spoke to were frustrated beyond anything when they couldn't have people come to see them for therapy, aphasia therapy, or whatever.

Bill Gasiamis 36:35

And it's kind of like they're doing, the therapists are doing their job to help rehabilitate people and get this speech back. But it doesn't seem to be any other part of the scientific community that's actively involved in supporting them to do

that. It's kind of like they have a little division of some of the work that they do this speech therapists and they do this work.

Bill Gasiamis 36:59

But although there's the kind of work that you do in the background, there's very little connection between individual therapists and the scientific community, although I know some speech therapists who are scientists and have and also have therapy organizations. So I know there's a little bit of connection, but there seems to be also a disconnect. Now, do you guys work specifically, with therapists sharing your findings? And then recruiting from there? How do you involve the therapists in your in your work?

Dr. Swathi Kiran 37:36

Right. So I mean, I understand what you're saying it is. It is a complicated, sub-optimal place where the average therapist isn't the regular therapist, I shouldn't use either of those. Any given therapist in the hospital does not feel the support and the resources necessary because they're fighting so many different battles. In the US, we try to make sure that our our speech and hearing organization that supports most therapists is aware of the scientific evidence that they need to convince the payers the funders, and their bosses.

Dr. Swathi Kiran 38:23

So the American Speech Language and Hearing Association, makes it its responsibility to translate the research to information that the clinicians can use is a perfect No, but at least that's there, that's part of their responsibility is to make sure that if a clinician who sees a patient says where can I go find help for this patient, they need to just go to this website and look up the evidence.

Dr. Swathi Kiran 38:53

And it will give them research evidence. But again, it's not perfect. And it is, what I worry about the most is it's not just that the speech therapist is not aware of Neuroplasticity, what they can do to harness that for the patient, and what's available out there.

Dr. Swathi Kiran 39:16

it's that the patients themselves the survivors don't even know what they're going to get if they stay at it, they're going to get better they are so this is something that worries me and I am trying to focus some energy on it now. But as soon as

you have a stroke, there's too much going on in your life. You don't have time to realize what's ahead of you. You're just in the mode of survival and get home and stay alive. And after that, especially for people who have aphasia.

Dr. Swathi Kiran 39:48

They don't even know what the effect of that aphasia is for a long time. That's why I brought up social isolation and depression. They realize they're never going to go back to their job because they even sign their name or read instructions. So it's a it's a huge period of adjustment.

Dr. Swathi Kiran 40:05

And there's very little information awareness education that's been given to the survivor and their family to, to get through that phase in life and know that there's, there's hope beyond that, you know, this is something that you're going to get better.

Dr. Swathi Kiran 40:22

And so that is where I've spent a lot of my time and effort more recently is making sure that the survivor knows that, yes, it's terrible. Today is two weeks after the stroke, it's, you know, I just need to stay alive. And at six months, yes, I'm still going to get better, I need to keep working at it. I think that is a message, we need to get out as loud as possible.

Bill Gasiamis 40:46

I hear you, I love it. Okay, that's good, because we get you guys who have the data into the space where you're talking about the data and the results that you're finding to directly to the end user, which is what's happening right now. And then, hopefully, the end user, if the therapist misses the data, or misses the information about what's possible, the end user can take that information to the therapist and explain to them what they've heard or what they know, or what they've discovered.

Dr. Swathi Kiran 41:18

Yeah, me just making sure that all the dots are connected, because no, no, no to know that, you know, then it's not a foolproof process right now. It's not perfect right now. So we do need to arm the stroke survivor with as much hope and information as possible so that they can go and ask their doctor, or their therapist, Hey, I heard if I heard that, if I keep doing therapy, I can get better.

What do you think?

Bill Gasiamis 41:44

Yes, yeah, I love it. And there's nothing better than motivated patients going to therapy because they have an idea of what's possible. And then they can go there and really sort of participate wholeheartedly in the therapy so that they can get the outcomes and be excited about therapy.

Dr. Swathi Kiran 42:07

I was gonna ask you, is there an unmotivated patient, a stroke survivor?

Bill Gasiamis 42:13

Oh, heaps.

Dr. Swathi Kiran 42:15

Yeah. Why is that?

Bill Gasiamis 42:17

Well, that's interesting, because I coach some stroke survivors, and sometimes I coach their caregivers, in conjunction with the stroke survivors, and I feel that some of it is related. And when I coach people, they think that I'm coaching them to get through stroke. But really, what you're coaching people to do is get through all the limiting beliefs that they've always had in their entire life, that are now a real problem because they have a condition that needs a different kind of focus.

Bill Gasiamis 42:48

And sometimes, I also find that stroke survivors are unmotivated because the people around them make them unmotivated. Because they could be surrounded by individuals who would say, oh, you know, why do you want to go to speech therapy? You know, and there's a lot of ill-conceived ideas about the fact that possible, all stroke survivors would want to approach recovery, like I do.

Bill Gasiamis 43:16

And not many do. Because I might try and model it because identity plays a massive role. So for example, the first thing that I tell my stroke survivors, whom I coached to do when they heal from a brain injury, like a stroke, is to stop eating sugar.

Bill Gasiamis 43:35

Okay, so I've nearly died, I've had to open my head up, to take a blood vessel out, so that I can survive. Yeah, there are hundreds of 1000s of dollars that have gone into that process. And I don't know the untold millions of dollars that have made it possible for a doctor to put me on a table, put me to sleep, and open my head.

Bill Gasiamis 43:58

And when they close my head, I'm still alive at the end of it. Right. And then somebody says to me, what you should do is quit sugar to help decrease inflammation in your brain and your body. The inflammation decreases will improve your capacity to recover, and heal, you will decrease the level of fatigue that you're experiencing, etc.

Bill Gasiamis 44:21

And when I say to them, quit sugar, they'll come back to me with 1000 reasons why they shouldn't including You Only Live Once You Know, including including bottom, a sweet tooth. But how am I going to go to the coffee shop with my friends I won't be able to eat cake. What am I going to do there?

Dr. Swathi Kiran 44:43

Psychosocial barriers and constraints that people go through?

Bill Gasiamis 44:47

Yeah, and alcohol is one of those massive issues. So when I quit alcohol, all my friendship group and I quit alcohol the day that I had the first brain hemorrhage, but all my friendship group said, Well, we're gonna go to the pub for a drink. And yeah, we'll go. When we get there, it's what are you having?

Bill Gasiamis 45:08

I'm having water. I'm gonna have a beer is that alright? Guys? You do what you do, and I'll do what I do. And we don't have to do the same thing. And you don't have to feel uncomfortable with me and not drinking alcohol. If I drink alcohol, I feel like I'm having another stroke. Why the hell would I drink alcohol?

Dr. Swathi Kiran 45:32

These are the kinds of lifestyle changes and psychosocial beliefs that you just have to work through so much even after the stroke, right? Not just before.

Bill Gasiamis 45:44

Yeah, it's the biggest part of my recovery is changing my identity and fighting the battles so that I could implement my new identity. And nobody else was feeling bad about the fact that I had a new identity. But that meant that I lost friends.

Bill Gasiamis 46:01

So if you're going to have a stroke survivor, who can't speak, and he's going through all these challenges, and they lose friends, because they are different or because their friends can't associate with them the right way, or their friends are emotionally naive, and can't have empathy for their friend and support different, it makes such a massive problem.

Bill Gasiamis 46:28

And what that could do for the stroke survivor is not make them unmotivated, because they chose to be unmotivated. But through social isolation, depression, and mental health issues, they could go you know what lifesaver for me, I'm not going down this path.

Recovery and rehabilitation using AI

Bill Gasiamis 46:46

And they come to a therapist for a failure, because insurance is paying for therapy, and then what do they do they just get there with? Is that high for me anyway, I'm just gonna go through the motions for my family. And then once the plateau is reached, and they tell me, I don't have to come here anymore. I won't come here anymore.

Dr. Swathi Kiran 47:07

It's yeah, you're you're right. And, in, my research, I see a lot of patients, I've seen people on both sides of exactly what you've described, I've seen the folks that are just trying to adjust to their new identity and fighting hard and doing it. Others have just given up as well.

Bill Gasiamis 47:29

Yeah, look, I would, I would write off my entire friendship group if I had to recover. Not because I want to, but because I come first. And if they can't come with me, then it's okay. We, reached our part in life, where we enjoyed each other's company, and if we have to go a separate way, they can go with my blessing, I have no issues about that. But I have to take it, I can't be the same me

that got me into the trouble that I was in. Now I had a thought in my head that I was born with. But I created the conditions for that.

Bill Gasiamis 48:05

To play up. I was smoking, I was drinking, I was overworking, I was always angry and stressed out. And I was never taken care of myself. So if I continued to be that guy after my recovery, there's no way you and I would be talking 10 years down the track. Exactly. So I drew the line in the sand, and I became a completely different person. And my biggest task became re-educating the people around me, the ones that didn't want to be re-educated, so to speak, they're not around.

Bill Gasiamis 48:43

But that's okay, I don't have an issue with that. I have a very different way of seeing things, a very philosophical approach to recovery in life and the rest of it. So I hope that what we're doing here is giving some of the people listening to it potentially have aphasia or other health conditions related to the stroke. Another way to approach life and to think you know, what, screw this, I'm going to for once in my life, life is short, I'm going to do it my way for once in my life.

Dr. Swathi Kiran 49:11

Yeah. And that is an I mean, again, 4,000% agree with everything you're saying. I think the only thing I would add to that is as a scientific community, part of a scientific community that wants to help. What we are trying to do is give as many tools in the toolkit to empower the survivor to say, here's the data that says Neuroplasticity, ism is not a method.

Dr. Swathi Kiran 49:42

It is something that happens. Here are ways for you to get your therapy at home. Here's the way for you to get engaged. So we're just trying to empower the person to say, I'm going to take charge of my life and not just give up.

Bill Gasiamis 49:57

Yeah, beautiful, beautiful You're doing some work at the University of Texas at Austin.

Dr. Swathi Kiran 50:05

That's my collaborator.

Bill Gasiamis 50:07

Yeah, tell me a little bit about that work.

Dr. Swathi Kiran 50:10

So that's a very long-standing collaboration I've had now for several years, that is a collaboration with a computer scientist Risto McAleenan. He is a well-regarded computer researcher who is, is well-known for building new machine learning AI models. So he was building AI models before AI became a thing he was one of the main people building those sorts of models, very intelligent self-organizing systems.

Dr. Swathi Kiran 50:47

And so what we are doing in that work is we're developing these neural network models is has become a common term now with other you know, with all this chat GPT AI, people talk about this a lot. But these are neural network models that essentially try to behave like smart brains. And so he is building the computer algorithms and the, you know, AI algorithms, and we're feeding him the data and the data could be is, is people's behavior, their therapy recovery.

Dr. Swathi Kiran 51:25

And that's what the collaboration is, is to use that to take the data and use these very smart, efficient computer algorithms that can be used to predict who's going to buy the next shoe, but they're now going to be used to decide who's going to who's going to recover, and how. And so that's a very, you know, these are the perfect kinds of interdisciplinary collaborations because you can use these AI models for health and for good.

Bill Gasiamis 51:56

Good instead of evil. Well, yeah, well,

Dr. Swathi Kiran 51:59

It's not evil. But in this case, it does make a difference, because you can try to understand why there's a difference in the data. After all, these computer models are good at trying to find sense, in a lot of noise. So that's, that's the expertise he brings, and the collaboration is to try to build sophisticated models of individual patient recoveries.

Bill Gasiamis 52:25

Yeah. So they seem like these guys are a very integral part of constant therapy, it seems to be the other part of this tool that you have available for people is that

you guys are doing the data collection, they are doing the processing of that data, they're using it for creating the models, and then they are combining all of that and putting it onto the platform so that people can access that right.

Dr. Swathi Kiran 52:53

Yeah, so So yeah, even the algorithm in in constant therapy is all very, very smart. Because it's, it's constantly learning based on the data that's being generated as part of people using the software. The UT Austin group is taking that data and trying to build different models, better models, so that we truly understand why people are different when they're responding to treatment. Some people get better, some people don't get better.

Dr. Swathi Kiran 53:25

Some people, you know, they take a break, and they come back and they, you know, their motivation helps them get better, so that it's trying to make sense of that so that we create better models that could eventually be used.

Bill Gasiamis 53:40

Fantastic. Have you seen

Dr. Swathi Kiran 53:43

at Boston University, the team is about 20 people, but the collaboration at UT Austin doesn't count in that because he has his big team of researchers, as well.

Bill Gasiamis 53:57

Yeah, it's fascinating. I love that stroke and AI has merged. You know, you hear about these things about AI that, you know, it's going to do, it's so fantastic that AI and stroke support and aphasia sport have merged and become a thing. And now, we're benefiting from that, you know, our community is so desperately in need of real solutions and real support, you know, that's cost-effective, and that's easy to access. And that means that we don't have to travel. One of the hardest things for me was traveling to my three appointments a week, you know, and finding three hours a day just getting to and from, and being at my appointments.

Bill Gasiamis 54:43

At some point becomes difficult, especially with a stroke brain to navigate that and have that and it keeps you in a way even though you're going to therapy, it keeps you out of the community because you don't have as much time for your community and Yeah, for the things that you want to get back to doing because

you have to be in therapy. So it's a real, real kind of challenge in navigating that whole process. So, if I had therapy available to me at home, I would have taken it up immediately, like I did.

Dr. Swathi Kiran 55:18

And I'm, A I'm a very optimistic person, though. So I do think that something good has come out of this pandemic. And I'm sure this is true in Australia as well. But even in the US, it has become clear that you have to make home-based health, home health available through video conference, telepractice, whatever that is, you have to make it available. And that's a good thing. That's the silver lining that comes out of this as well. Likewise, in this, you know, in this age of AI that's affecting everything in our life, again, the positive silver lining for all this within with a stroke, and health and recovery are, in the past, we would be very scared to say, no two people are alike.

Dr. Swathi Kiran 56:05

So I can't help you. Because you're so different from the person I saw before. I don't know what to do with you. But now we can say, well, you're different and our data can model those differences. And that is another huge technological, scientific leap that's happened that allows us to say you might be different from the next person that walks in, we can help you. Whereas in the past, we would say, Oh, we don't know what to do with this. Yeah, everybody looks the same. Let me tell you what's going on.

Bill Gasiamis 56:36

Yes. So there's nuance now there are individual applications rather than one size fits all? Right, exactly. Yeah, that's cool. Now, you know, some of my listeners and community, the stroke survivor community, some of those guys, they're going to go into parts of life, you know, maybe even me, you know, with dementia, and Alzheimer's might be an issue. Now, this is, what's cool about what you're doing is that it's not just applicable to one aspect of the community, you're specifically working with stroke survivors.

Bill Gasiamis 57:12

But have you done work with people experiencing Alzheimer's or dementia? And if not, is this like easily just like applicable to them? Or do they have more unique things that you need to take into consideration?

Dr. Swathi Kiran 57:28

Yeah, that's a great question, though. , there are two parts to this. A lot until very recently, I would say five years ago, somebody was diagnosed with dementia, it was even worse than a diagnosis of stroke, because people would say, go home and die, because we can't help you this is, you're just going to get worse. And after a while, you're not going to remember anything. That is not what's happening. Now, as you know, some drugs have been approved for dementia.

Dr. Swathi Kiran 57:58

And there's quite a bit of scientific evidence showing that people who are diagnosed with dementia, if they practice therapy, they do, you know, focus therapy, memory therapy, they actually can maintain their skills for a while. So in that context, whatever works for in the context of something like constant therapy, or any other therapy, those exercises, as you mentioned, brain HQ, they are working on attention and memory and focus, they will help people with dementia as well, as long as they can practice it fairly regularly. So that's good.

Dr. Swathi Kiran 58:33

That's a piece of good news. And then the second piece that I want to say is, that we are extending all our work into dementia as well because what we have understood and you've mentioned this earlier in your podcast is that it's not just the stroke that affects someone's brain, overall health affects the brain, what you eat, what your other lifestyle choices are all affects not just your body, but your brain as well.

Dr. Swathi Kiran 59:02

So what we are doing and other people have found is that in addition to what the stroke is done to the brain, there are other things in the brain's overall brain health, that also predict whether somebody's going to get better or worse in time, and that's where some people with a stroke will just get better and you know, they'll live fine. Other people with stroke are already at risk for other things because of their health or their cardiovascular risk factors.

Dr. Swathi Kiran Documenting

Neuroplasticity



Dr. Swathi Kiran 59:28

And they're actually at risk for decline because the overall brain health is not as strong. So our group and other groups are starting to look at that now because again, you can look into the future. And you can say with this sort of overall brain health profile, you know, you may not be, your prognosis may not be as good as someone who has a different brain health profile.

Bill Gasiamis 59:57

Okay, that's good for the first time. So what we're doing is going into therapy, not only with, this is going to help you speak better, but also this as well, this other thing that you pay attention to is going to help you speak better, as well as the therapy is also going to help you speak better.

Dr. Swathi Kiran 1:00:16

Right, we're trying to understand all those factors. And, there seems to be this continuum of what the brain looks like when someone just has a stroke and what the brain looks like when someone has dementia.

Dr. Swathi Kiran 1:00:30

And there's something that's changing in the brain in that process. And we are trying to understand how to document that so we can exactly show where people have a potential for recovery, or whether the higher risk there's these are not isolated conditions anymore. They're all different kinds of the same problem that the brain is going through.

Bill Gasiamis 1:00:54

You know, in this podcast series, you know, we're up to I think your episode will be something like 267, 7, 8, 9, somewhere, there

Bill Gasiamis 1:01:03

is a little bit of a research project. For me, it's a whole bunch of data. And I see some patterns that emerge. And recently, one of the people who hasn't been on the podcast, who's doing it quite tough, who I've kind of supported a little bit via email,

Bill Gasiamis 1:01:20

has told me, you know, where are all of the stories from stroke survivors coming onto your podcast, who are doing tough with, for example, a spouse that's making recovery hard. So you spoke earlier, about people who are not motivated to recover. This particular gentleman has a spouse who is separated from him and is making his life difficult. And that's getting in the way of his stroke recovery. And he was saying, he was saying this out of frustration and anger because of the situation that he was in amongst all the other situations that he's in with his health.

Bill Gasiamis 1:01:59

And what I realized when he said that was that I don't pick my stroke survivors who come on the podcast, they pick me. I asked some of them if they wanted to be on the podcast, and some of them, said no. And some of them say, yes, there's aphasia, people with Aphasia that have been on the podcast, even though most, even though that's not a very fluid and quick episode to listen to, right? But with editing, you can get rid of the pauses and the stops, and we can make it cohesive, and it sounds like a very decent conversation.

Bill Gasiamis 1:02:39

And it shares the story of somebody experiencing aphasia, and recovering from it and going after recovery. Now, other people won't come on the podcast, and they'll specifically note, that the reason is, is because I have aphasia. And that says to me, something about the fact that the people who do come on the podcast, whether they have aphasia or not, are having a better stroke recovery than the people who choose not to come on the podcast. Because they are, they are talking about it, they are sharing so other people can learn and help them and help other people. They are getting it off their chest, they are getting their story there.

Bill Gasiamis 1:03:24

The turmoil, their condition, all of their chests, you know, they are sharing it with the world, not just this gets downloaded in 60 countries, it's not just me, they're talking to the sharing it with the world. And I've seen this pattern that the kind of person that comes on this podcast is having.

Bill Gasiamis 1:03:44

This is not a very scientific word, I better stroke recovery than the person who's not coming on the podcast. So it's just something about getting involved and participating. And being active and making it potentially about somebody else is supporting recovery, and is supporting the work that your therapists are doing, that you guys are doing. It's all together. You know, we're all we're an important piece of the puzzle. We all got to work together to solve problems for us, and then for the people coming after us.

Dr. Swathi Kiran 1:04:25

Yes, you're right about that. And I think the best you and I can do is empower the people who are brave enough to come to your podcast, get out in the world, and try everything they can try every day even though it's hard for them and then motivate the folks who need that little bit push to get out of their house. They're the ones who need the most help because it's much harder for them to get out of their house. You know, I mean I was like, get out of their shell. Yeah. And and try. Yeah, that's what I can do: to give them different ways to feel motivated and try every day.

Bill Gasiamis 1:05:11

Yeah, I love it. As we wrap up, I'd love to ask you if there's one takeaway from this whole discussion that we've had that you want the people listening, caregivers, therapists, and stroke survivors if there's one thing that they could take away from this episode, is there something that you could share?

Dr. Swathi Kiran 1:05:35

Bill, I want every one of your listeners who's had a stroke, to know that the worst part of the stroke is having the stroke. After that, the brain has this phenomenal ability to recover, and reorganize. Neuroplasticity happens in the brain. And there is no time limit for that. You have to try different ways because not one approach will work all the time. You may have to try something and if it doesn't work, stop, come back, and try something else. But don't give up because every bit of the

scientific data suggests that your brain can take this on, and keep working on the recovery.

Bill Gasiamis 1:06:22

Dr. Cure, and this has been an amazing conversation. Thank you so much for the work that you do. Thank you for being on the podcast. I appreciate it.

Dr. Swathi Kiran 1:06:29

Yeah, it was great to chat with you. It was great to talk to you. Thanks, Bill.

Bill Gasiamis 1:06:34

Well, thank you for joining me on today's episode, it was a cool conversation. I hope you got a lot out of it. To learn more about my guests, including links to this social media and other pages, and to download a full transcript of the entire interview, please go to [recovery after stroke.com/episodes](https://recoveryafterstroke.com/episodes). Thanks to all those people who have already left the review. It means the world to me and you are helping others in need of this type of content to find it easier, and that is making a difference in their recovery and it's making the recovery just a little bit better.

Bill Gasiamis 1:07:10

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Intro 1:07:37

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Intro 1:08:11

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Intro 1:08:39

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Intro 1:09:02

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