Introduction and Rosalind Kalbu2019s background

Okay. Rosalind, I am so thrilled that you agreed to be part of the M. S Neuroimmune Summit. You have such an important mission, you're doing such important work.

Now, what I'd like to have you do is introduce yourself and tell us briefly why you have this area of expertize. I'm thrilled to be here. Thank you so much for inviting me.

My name is Rosalind Kalb. I am a clinical psychologist, and I've worked in the field of M. S. proudly and gratefully for over 40 years. And I've learned a lot from people and that's about what their priorities are and what they need.

And it is my pleasure and my goal to help them get what they want for their own care. Now, Ross, I am again so glad to have you. And I know you've been working clinically for decades for people with M. S.

and we're really curious as to what that journey has been like and what has changed over this time. I've actually given that a lot of sort of recently, because when I started in RMS, I was at the first university based comprehensive care center in the country, and it was just by chance.

I didn't know what RMS was, and I got a job there and I learned from a true comprehensive care team what real mis care needs to involve in order to meet the needs of individuals with MSC and their family members.

And you have to remember that in 1980 we had no disease modifying therapies and MRI. The technology of MRI had just been invented but wasn't in use. So if you think today about what takes up the time in an EMS person's neurology appointments, it's frequently the talk about the DMG, the disease modifying therapy.

Should you be on it? Do you need to change the one you're on? How do you manage it? How's it working? And let's look at your most recent MRI and then the apartment.

The appointment is over right? Leaving people with Ms. and their family members with many questions never get answered.

How MS care has changed over time

In 1980, in the absence of the disease modifying therapies and morons, our clinical team focused on the health and wellness needs of people living with a chronic, unpredictable disease.

So the focus was on their mental health, their rehabilitation, their bladder and bowel issues, their mood and cognitive changes, their employment challenges.

Every thing that you can think of today that challenges life when you have a chronic, unpredictable illness, because that's all there was to do. And I think over the years, obviously, we've benefited from the 20 plus disease modifying therapies that are available that have been life changing and must changing for many, many people.

And certainly MRI's have given us an insight into the disease process and the progression. But what we've lost in those important interactions is the true multi-disciplinary symptom management and wellness for people with M. S.

and their families. People aren't getting it. They don't know how to ask for it. There isn't time for it. And because the neurology community is so much focused on the damages and MRI results, people with M. S.

aren't even aware what an important role their physical health and their wellness needs play in how they live with them. You know, this is why I'm so thrilled with the work that your organization does and that you're part of this

summit, because we need it for everyone who's listening.

If you have M. S. or other neuro immune conditions, there are things that we can do to support your wellness journey. So let's sort of dove in. What is wellness for the messenger immune patient?

What does that look like? I think it has many components that all contribute to one's overall well-being and to their journey with a chronic illness. So if you think about just starting with the physical aspects of wellness, yes, it's taking your medications and yes, it's doing what your neurologist suggests that you do.

But it is also paying attention to your preventive care. Any co-morbid health conditions you may be living with, to getting the adequate amount of exercise and physical activity which we now know is so important to eating a healthy, balanced diet.

That's just sort of the physical components. But then there's emotional well-being and how are your relationships and your communication with important people in your life and what's happening with your career plans and your ability to continue to work at your chosen field for as long as you want to, and your spiritual well-being, because how you are grounded in whatever way is meaningful to you, how you are grounded in the world around you, and what gives meaning to your life also gives meaning as you struggle with a chronic, unpredictable disease.

So these these things all come together to support whatever else you're doing to manage the M. S. disease course, people need to understand the impact of those other elements.

So people who are who are listening to our summit, they're like, Yep, yep, those are really important. But I'm not getting that from my my primary care doc, really.

I'm not getting that from my neurology team. Where were where could they turn to get those kinds of needs addressed? So this is now very, very close to my heart.

But I'm saying it with every I'm saying this with heart and soul. I think that many organizations are trying to facilitate wellness and personal care that people with homes and their family members can take of themselves.

But I'm I'm I work with an organization called Can Do Multiple Sclerosis. Oh, well, you went a little faster. Can we slow that down again, the name of your organization.

And do multiple sclerosis. And interestingly, it was started many years ago by a man named Jimmy Sugar, who was the first American to medal in downhill skiing at the Olympics.

And shortly after he won his bronze medal, he was diagnosed with Hamas. And at that time and he actually came to our center for some help. He went to many centers, but he kept being told that what he needed to do was change his life course and rest and stop being as physically active.

He did not hear that at our center, but he did hear it in general that trying to do what he was doing as an athlete wasn't going to work for him and he couldn't deal with that.

He could not tolerate he had been a trained athlete his entire life. And so he said, I'm going to make my own street meant for my multiple sclerosis.

Defining wellness in MS care

And it's going to involve being very physically active because I feel better when I'm physically active and I'm going to eat right and I'm going to surround myself with people who support my way of doing things, and I'm going to create a community.

And it worked for him. It didn't change his whole disease course, obviously, but he had changed his outlook on his life. It's changed his quality of life and his in his love of living.

And he skied, although with some adaptive equipment later in his life. He stayed until right before he died. So he wanted to bring that wellness orientation to people with them instead of telling folks with them as what they can't do anymore.

He wanted to help them figure out what they can do and what they can enjoy doing and how to thrive and live joyously, even with a chronic illness. And so he started to bring together not only people with them and their support partners to learn together, but he recognized the importance of a multidisciplinary team approach.

So from the very beginning of this program, it has always been health care professionals, different disciplines who share their expertize and work as teams.

No matter what program we're doing to help people achieve wellness in all the areas that are available. But they get to choose and focus on which areas of wellness are most important to them.

You know, Russ, as I listen to you, I think he also talked about what mattered to the person. So if it's athletic, I'm guessing maybe if it was cooking or a writing or painting, you're probably creating programs that help me in the first month.

I might achieve that part of living that speaks to my heart and soul. Would that be correct? I think that's exactly right. I think his feeling was it's not up to the medical community to decide what's important to you as an individual.

Right. I love that. It's for the medical community to help guide you in the management of whatever illness, whether it's a mass or some other illness, how to live with it according to the science that we know.

But for the individual and the family members, it's what matters to me, what brings joy to my life. And if I can't do it exactly the way I used to, can you help me figure out new ways that I might be able to do those things that I loved or could you help me identify some other things that I might never have tried before because I never had to try them before?

But what might I try now that would add interest and joy to our lives? Because I think one of the things that happens, whether it's our mass or aging or another chronic illness, that if we're not careful, our life space begins to shrink.

Right? I can't do this any way the way I used to, so I'm going to stop doing that. And then I can't do this and I can't go here and I can't do that because I can't do it the way I did.

And suddenly people find themselves living in a less interesting life space. They're not as stimulated, they're not as interactive, they're not as adventurous because they don't know how to do those things with the limitations of mass.

And so what I can do, tries to do is to help people keep their life spaces interesting and exciting and small as they want them to be, because that's how we thrive, regardless of what limitations are coming into our lives.

You know, everyone who's listening, we've we've learned about neuroplasticity as we do less and less and less. My brain is learning to do less and less and less, and the speed of my disability accelerates.

What Roz has just taught us all is it is so important to keep our life as fully enriched and engaged so we can keep that neuroplasticity going in a good direction.

And that's okay if I have to learn how to exercise in a different way. You know, when I was an athlete as well, when I quit running, I'm like, okay, I'm going to have to swim.

I wasn't a very good swimmer, but like, okay, I guess I'm going to have to get better at it because I knew that if I quit exercising, that would be really terrible for my brain.

And I and I think people discover talents they didn't know they had interests that they didn't know were of interest to

them. They find other ways to connect with people in their world and that kind of self-discovery discovery is good for all of us.

Hopefully, as we go on in life, we will always be continuing to discover new parts of ourselves and cultivate those. And I think, Jim, you really believe that to his core.

And that's what the can do.

Can Do MS and the wellness model

Programing tries to help each person do and I really want to emphasize each person because one of the things that I am most proud that Jimmy did and proud that we continue is for us, same as is not a me disease, it's a weed disease.

And one of our participants actually coined that phrase and it is so true that when one person in a family is diagnosed with mass, the whole family is living with that, whether it's spouses and partners or children or elderly parents, the whole family system is living with that.

And I think she recognized that and he recognized how important it was that our programing, our focus as much on the needs of those family members as on the person within that, because it's that teamwork, that mutual support, that ability to communicate what's going on is so vital to the health of these families.

Because when you think about it, most of them is invisible, right? Yes. It's that old, you know, tip of the iceberg or just those few missed symptoms that you can see in somebody walking down the street.

But the things that really impact employment and relationships and communication and engagement with the world aren't visible. They are the mood changes that happen with them as the cognitive changes that impact how people communicate and how they form in the workplace and pain.

You know, when I started in 1980, people were being told there was no pain in EMS. Oh, there. Were no cognitive changes. And it was really that baby boomer generation that spoke up self advocate, right?

Even before that term was being used, self advocated and said, stop telling us this disease and some people stop telling me it's not affecting my thinking.

Of course it is. Would you please help me figure out what to do about this? And that helped to support people in the family as well, because the support partners are struggling to understand what they can't see.

They can feel it because of the cognitive changes, the mood changes. They can feel that their loved one is struggling, but they can't see it. Yeah. So a support partner says to me, I wish my wife had a gas tank on top of her head so that I could just look at this meter, this thing, and tell me whether her tank is half full or half empty or just totally empty because I don't get it.

Yeah, right. You know, so such an important need. Where are where does can do exist. And I'm thinking so people listen with M. S. so I've a couple of questions.

First one, do I have to have EMS to be part of can do what if I have a motor what if I have rheumatoid arthritis and I'm having a lot of pain and cognitive issues?

Could I participate in a can do event? It's a fabulous question. And we were actually just talking about this morning, our our dream. Our dream is to take this model of wellness care and expanded beyond M. S. to normal aging, to other neuro immune diseases, to whatever.

I think right now somebody could certainly, for instance, somebody living with Parkinson's could come and listen and participate. And many of the issues would be exactly the same.

But the resources that we talk about are specific. Okay, so now the next question is, so I'm living here in Iowa, and I know we have a million people in the United States, many of whom live in rural America, who have drive three or four or 5 hours to see their M. S.

clinic, maybe once a year or every other year, depending on the resources, they are going to have a can do resource in their community. So how how can they access this amazing programing that you've we've just been talking about.

How they do have it in their community. I'll tell you why. One of the good things that has come out of Komen and I don't know that there are very many things that have come out of COVID that we value.

But one of the things that that came out for us was that within a two week period, we had to pivot from what was our flagship in-person four day program that was going to take place in Atlanta.

And we couldn't do it because of COVID restrictions. So in that two week period, we pivoted to create an online interactive health and wellness experience for people with masks and their support partners.

And that model was so successful over the COVID crisis that we made an important decision. One was that we would never give up in-person programing completely.

Family impact, invisible symptoms, and self-advocacy

So last year and this year we're doing four in-person programs partnering with different mass care centers in the country. But all the United States. On the United States that most of our program is going to continue to be virtual.

And there are a couple of reasons for that. One is the one you mentioned. So many people are living in rural areas who cannot possibly travel to in-person programing.

No matter which organizations providing it, they cannot get there. It's too expensive to travel. It's too exhausting to travel. So we are now offering many opportunities each month for people to gather from the comfort of their own homes.

And we had on our last two day program, we had people from Austria, from other parts of Europe. We also have several Canadians, as well as people across the continental United States who gather for the different types of programs.

And I'm hoping you're going to give me an opportunity to describe those. Oh, absolutely. They come together virtual to share and learn and connect with one another.

And it's all of those programs are again presented by a multidisciplinary staff of people who live all over the country. The core of the core team of can do and this is very small, like 20 people.

Okay, but the breadth of the care comes from over 100 health care consultants like myself in psychology, neurology, nursing, rehab, speech, language pathology to come together to do programs.

Now, Roslyn, this is wonderful. Now, I'm going to ask you a couple more quick questions. Are you doing this in different times of the day so my Australian friends can show up, my European friends can show up.

So it's a challenge. Just the time zone challenges it is is a difficult one. But I can tell you that those folks from Australia that are really, really early like in the middle of the night to participate, but we do try to balance things so that there are some daytime programs, some evening programs, just trying to be sensitive to who on the West Coast the United States has to get up at a reasonable hour.

And who on the East Coast of the United States has to go to bed at a reasonable hour and we try to move things around so that everybody has some access to the goodies, plus things like our webinars are are always archived.

So you could. Yes. What one could attend live and one could watch the recordings. So of some things you can watch a recording of the webinars because they are the participants are anonymous.

But in our more interactive programs, which I'll describe to you, we can't record them because we would have to get permission. Yes. Hundreds of people who participate more.

More complicated. Yeah, it's more calm. Okay. This is more of us. I'll tell you. So we do virtual events as well. And what I've learned is if you have 6 hours time spread, so there's a noon and a evening in an early morning, we can we can tolerate that in the U. S.

and people around the globe. If I can have that kind of spread, they don't mind getting up early, staying up late if we'll have that kind of spread. But for everyone who's listening, the challenges that Roslyn is describing, those are the challenges that I face.

My staff live here in the United States as as do her staff. So I can't make them get up in the middle of the night. So we try to stretch it in terms of what other reasonable times we can ask.

Our people who are doing this on a volunteer basis. Usually out of the goodness of their heart. So the fact that they're willing to get up really early or stay up late to make it easier for our world partners is good.

So what are some of the programs that that you guys are doing.

Virtual programs, access, and participation options

So our mantra is that we want to do programing that provides some information but then also offers opportunities for connection and then ways to activate or act on the things that you've learned to reach the goals that you want.

So with those things in mind, information, activation and connections. Each month we have one webinar which is probably our only more straight, straightforward, didactic type of programing.

They are still interactive to the extent that we can make them so, but we may have seven or 800 people on one of those webinars. So that that lays the baseline of information for the topic of the months.

Right. And the topic of the month may be symptom based or maybe employment based or maybe something else after that introduction that's somewhat didactic.

Then there is a two hour program, multidisciplinary again in which a group of people comes together. They're reminded in case they didn't hear the webinar of the sort of basic information that we're talking about.

And then they immediately go into small breakout rooms where they work with health coaches, facilitators of different disciplines to answer some questions to problem solve together around whatever the topic of the month is.

So let's say was a bladder and bowel month. Then you have a room of 15 to 20 people sharing strategies that they've learned, challenges that they confront, how they self advocate health care team to get help for the symptoms that they have.

But mostly it's to connect and bond over the fact that each of them living with bowel and bladder challenges isn't alone, that this is a safe place to connect, to talk, to share, to laugh, to cry and then leave with some personalized goal that they want to work on in their own lives.

Then the third program is a month is just a time to ask questions. So you come to a webinar or you go to a program, you didn't have time to get your question answered, or you were too bashful to bring up your question.

And now it's an hour and 15 minutes. We're all we do is answer the questions. And and I'm going to ask some of those questions are pretty tough to say out loud.

How do you manage pooping in your pants? How do you manage low sexual desire? How do I manage the fact that my partner doesn't really want to have sex anymore?

Those are you know, that's pretty hard to have someone raise their hand and say those things out loud. So is there a way to ask really hard questions anonymously?

Yeah, I'm going to I'm going to make that a two part answer, Terry, because I think these things happen. You can not show your face at all. And these programs and you can type a question into the chat room or you can send a question to can do at any time.

And type in your question and somebody of the appropriate discipline will answer. So yes, there are absolutely words to stay. As private as you need to.

Is private is. On the other hand, what we have discovered is that when you gives this baseline of information at the beginning of the month, which kind of normalizes some of these uncomfortable topics for a whole month about sex, sex and intimacy.

So you lay the groundwork and they realize that a lot of what you're experiencing is EMS related. It's not some other thing that's going on with them.

And then they come into these small breakout rooms. They talk, they talk. This is beautiful. Camera or they don't come on camera, but they they say things that and this is mixed sex and gender.

I mean, this is people just feeling like this is a safe place to talk if they want to to listen, if they want to take away whatever they need and the feedback we get, one thing we hear all the time, I am not alone.

This is not just my problem or just my symptoms. So now I can ask about it and I can self advocate with my health care team. So yes, it can be private or it doesn't have to be and it's safe.

Program formats, anonymous questions, and takeaways

This is wonderful. RAAS, I could talk for hours with you. This. This is just so important. In some ways. This may be the most important interview that I that I will do for the summit because this is such a unmet need.

So, again, for all of you who are listening, whether you have M. S or a other neuro immune condition, I hope you will look at the can, do resources and consider participating in some of their events.

I predict you and your family's lives will be changed for the better. Now what is the one thing, the one take home message you want people to take from this interview.

Of endless opportunities to create your own path? So if you learn some information about what you're living with, you figure out what your priorities are as an individual family, and then you can get the help you need to advocate for yourself with your health care team and get your life where you want it to be so you can thrive.

You know, it's my dream that this summit goes out to all million people here in the US and all 2.8 million people in the world. Now that's a pretty bold dream.

I don't know that we'll quite hit that, but hopefully this will get out to hundreds of thousands of people. This is such a profound, profound message.

Now, where can people find can do so? Come to our wonderful new website at WW W dot and do hyphen m s dot org. We will welcome you with open arms and help you connect with whatever you need.

That's right. And we just told everyone, you don't have to have M. S. You get to come even if you don't. And this has just been so wonderful one more time.

What's the website again? And do m M. S. dot org to open up the world for you. This is wonderful. Thank you so much. Thank you for the opportunity. It was fantastic.