Introduction and Hollie Schmidtu2019s Background

Welcome to the MS and Neuroimmune Summit. and, Hollie Schmidt, I am so, so glad that you are part of the summit. let me read your bio. Hollie is the vice president of scientific operations at Accelerate Cure project for multiple sclerosis.

She co-chairs the research committee for of I conquer M. S., which is how I met Hollie she's a virtual participatory research network for MS Established to perform and support this key concept.

Patient centered research. and she wants to develop research of the. That's relevant to people with MS She founded and leads the MS Minority Research Engagement Partnership Network, a multi-stakeholder initiative aimed at promoting racial and ethnic diversity and MS research studies.

She's the co-leader of I conquer MS Right. Research. Inclusion. Diversity. Equity. Council. and, that's how I met Hollie We've done some interviews together.

I so appreciate what, the Accelerated Cure project is doing. so did I. Did I leave anything out that you'd like to touch on? Hollie? No. Nothing important.

I think those are the highlights. Okay, so let's talk about I conquer M. S. and Accelerate cure. Can you tell us a little bit more about that wonderful organization?

Sure. Yeah. We were founded, a little over 20 years ago by a good friend of mine who was diagnosed with MS Himself. and he is, an entrepreneur or, high tech person.

and wanted to know, you know, what's going on in MS You know, are there any cures, are there any treatments? What do we know about it? And I came to find out this was, you know, 20 or so years ago, there wasn't that much known about it.

How Accelerated Cure Project and iConquerMS Began

We didn't really understand what causes it. we still don't quite exactly know what causes it, but we have a better idea about what the risk factors are.

at that time, the treatments that were available were very few and not that effective. And, there wasn't that much collaboration among scientists either.

people had their labs and they kind of worked on their own. And coming from, you know, business in high tech, obviously there's, a lot to be said for working together, for coming together, you know, what do we need to do?

How can we accomplish it? By sharing, how can we make things open access so that people, multiple people, can take advantage of the same things? And so he founded Accelerated Care Project with, that kind of, philosophy in mind.

understanding what's happening with the disease and then creating resources that scientists can take advantage of from all over the world. So, since then, we've, established a few different resources.

Our first one was, a major bio repository. So blood samples from people with MS And controls that could be shared, by any scientist anywhere in the world that's doing good research.

they returned their data to us so that we can further share on the results of their projects. we also have AI

conferences, which is what you mentioned.

And this is a virtual network of people with MS, again, located, in many different countries all over the world who sign up because they're interested in research and they want to get involved.

They want to participate in studies. They also want to share their own ideas for what studies should be happening. You know, what questions they have that they feel are important to answer.

And, and also to get involved in the running of the network itself. so that's been around since 2014. We're coming up on our ten year anniversary. like I said, anybody can join you go to AI conquer MS dot org.

Create an account and then be notified about different ways of getting involved. But we supported a number of different studies and have more coming forward in the future. You know, they really appreciate that.

You gave, my lab an opportunity to come talk to your audience. And then we, spoke with, the AI, the, minority group, because it it is important to have greater, racial diversity.

can you talk about some of the misconceptions about research that might be out in the public? Yeah, there are lots. And I think, and it's especially important, like you said, for, you know, people who who come from groups that haven't traditionally been included in research or have even potentially been harmed in research, it's important to make sure that there's factual information about research.

You know what it does, what it doesn't do. who is it for? And, you know, so that everybody can consider it for themselves. And again, on a factual basis.

So some of the misconceptions that are out there, a lot of people think of research as being primarily drug studies. So, you know, if you go into a study, you're going to have to get randomized to a drug or you might be on a placebo.

you know, that's not the case. There are all kinds of studies out there. drug studies obviously, but other kinds of therapies that don't involve drugs or question, you know.

What are some of those therapies? Yeah. Don't involve drugs that that might be part of a research program. Right. So there's, you know, complementary and alternative therapies.

So things that a lot of people are interested in like, you know, acupuncture or massage or yoga, those are some of the therapies. there's also lifestyle approaches.

So you all know that diet is something that a lot of people are interested in. And that's something that, is being researched, your conducting research.

and that's really the way to find out whether a diet is appropriate and helpful. And in whom, for whom it can be most helpful.

Research Misconceptions and Types of Studies

exercise also is a very active area in MS a lot of different groups are doing exercise studies, and it's interesting people with MS used to be told don't exercise is not good for you.

You'll overshoot. Yeah. And that is absolutely not true. You absolutely do want to make sure you're not overheating. But as long as you can control you know your temperature then exercise is very healthy, very good for people with Ms..

Good for just about everybody. but there are a lot of, scientists out there who are exploring different types of exercise, what levels of exercise and what people can expect.

if they do embark on an exercise program. So let me summarize what I think we've, that we've just heard. Yes, there are drug studies. there are probably supplement studies where you take a particular supplement or a supplement cocktail.

Yeah. there are studies where there's a specific exercise, type. and some of these exercises might be balance exercises, yoga, strength building, aerobic exercise.

So, so they may be comparing different types of exercises. And then of course there are diet studies. And people know that I do diet studies. But there are several other scientists now that also are studying various diets as well.

and would it be accurate to say that if you're in an intervention study, we don't want you to do two different intervention studies? So pick one. Do that for the duration of that study, and then there may be other intervention studies that you can do because, the scientists we all want you to do just one intervention at a time.

If you're in research, if you're in my clinical practice, yes, we do lots of, you know, lifestyle interventions at once. But in a research study, we'll pick one that we're studying at a time.

Yeah, exactly. so how can people find learn more about research opportunities to pick one that, they may want to participate in, right. Yeah. Well, like I said, I, I conquer MS which you can get to at iconquerms.org is, where you can sign up and we can notify you we have a longitudinal study.

That means a study that happens over time called real MS You can participate that in so they're your data. what. Is real and about. Let's hear a little bit more detail there.

Yeah. Real MS Is a study where we are collecting data from people over time to find out how they're doing with their Ms. and then also what they're doing with their MS So we collect information about their type of MS any drug, their drug treatments they may be taking or any lifestyle and diet they may be following.

and, hang on. Is that what we call an observational study? So it is observational, right. So we're not asking you to change or try anything you can if you want to, but we're really just asking you to record, you know, how you're doing, how your symptoms are and then what you might be doing in terms of treatments or, lifestyle approaches.

It would people need to come to you or can they participate from their homes? It's all virtual. Right. So that study you can do from your homes, wherever you are, you can do it on your, you know, desktop, laptop, mobile device.

whatever kind of device you have, you just need an internet connection and the ability to get on a website. And you. So you could probably participate from anywhere in the world.

Anywhere in the world. Yeah. But. Okay. I want to stress that one more time. This is so important. it is so helpful to have more people in this longitudinal study.

If you're listening and you're over in Europe or Asia or Australia or the Pacific Islands, we want you. If you're in North America, South America, we want you.

I want you to be part of this, patient registry. These are incredibly valuable, resources. I've been part of, a longitudinal study, for years, for the, now. Oh, my goodness, 13 years that I have. MS I've been in a longitudinal study for ten years.

it's like one of those data points showing that. Yep, things can get terrible, terrible, terrible, terrible. And oh, my goodness, things get better, better, better, better.

iConquerMS Real MS Longitudinal Study

and so that information can be captured and then analyzed by other scientists. Exactly. Yeah. So hopefully we've just gotten, I'm hoping a couple thousand more people into your patient registry for you.

and so if I sign up for this and I'm doing the, how long, how long does it take me to answer the questions for your longitudinal survey? Is that like a five minute commitment to half hour commitment?

A two hour commitment? What's probably more like half an hour, but you can they come in different survey so you can do a couple. You can come back to it later.

you know, do a couple more. So there's no requirement to do it all at one time. And then every six months we'll ask you, hey, come back, you know, give us an update if things have changed.

We want to know if things haven't changed. We also want to know that as well. That means that you know you're stable, and it's important to understand the factors that lead to stability.

And if, things are getting worse, of course, we want to know. Right. And so how how long will people be in this longitudinal survey? Would it just be like forever that I could participate in it for the rest of my life, which hopefully in my case would be another 60 years?

Yeah, we'll see. Yeah. And so people can can do this periodically for the for as long as they want. This is profound. These types of like true surveys are really vital to understanding what are the environmental factors that contribute to stability to improvement or decline.

Right. And it's open to everybody. And that's another misconception that some people say, well, I'm too old. researchers don't want me or I don't have the right subtype of mass or, you know, I live too far away from a research clinic, real. Ms..

And there are other registries as well. you know, we're open to everybody, regardless of your age or level of disability, your subtype. On regardless of age.

So, yeah, but children, lots of space. So, how do we handle that? We actually just launched, last year, something called I Conquer Ms.. Kids and teens.

So that's for pediatric Ms.. And so, yes, we do have a way for kids and teens and their parents and family members to also get involved. It's a little bit different because children can't consent for themselves.

And consent is an important part of research. You need to be explained. You know, what it is you're getting into and what's required. And how can you, you know, leave the study if you want to.

All of those things have to be explained. And children, if they're not at the age of majority, they can't necessarily do that for themselves. So their parents have to consent.

And then the child has to also agree to be part of it. So it's a ton of different platform. It's, you know, yeah, I can't promise kids and teens, but it's also for pediatric EMS, a great way for any child, any teen with the permission of their parents to get involved.

You know, it again. I want people who are listening, who have who have children in their lives. we we don't have as much research about children because of the complexities.

we have to, have the parents consent. so we do need more opportunities for research like this so we can understand what are the factors for children. Yeah, I know, one of one of the, I'm not as familiar with pediatric M. S., but one of the studies did show us that diet in kids is really important, that eating more vegetables turns out to be really, really good for our children in that eating more saturated fat and, in more processed food.

Fast food is really bad for our children. And that, increases the risk of Ms.. It increases the risk of, more severe Ms.. And we we got that from some other longitudinal studies, of children.

If you again if you have children, if you have teens who have Ms.. I encourage you I'm going to have you give us

the website again. Holly, please think about participating in this pediatric research.

It'll be so helpful to our understanding of how children are impacted by this disease. Holly, can you give us that website again? Sure. So I concur, Ms..

Morgan. That's spelled I c o n q u e r. Ms.. Morgue is the website, and that's the sort of the parent website, the original one.

Pediatric MS and Caregiver Research

So if you go there and you click join now, you should be able to sign up for that are the kids and teens. And we also now have launch one for caregivers as well.

So this is called Research Site for caregivers. Yeah. because I know when I, you know, before the, pandemic, I would host a live event. People would come from all around the world, and we were just beginning to have special sessions for the caregivers, in the partners.

so, tell us more about, what you are doing, for the caregivers and partners. Yeah. So, you know, caregivers are a really important part of, providing care and support for people with Ms..

Usually this is a family member, a spouse or a parent or an adult child or even a younger child. but there's somebody that tends to live with the person with Ms.

can help them out with their physical needs, but also with, you know, cognitive support, emotional support, you know, everything that is needed. And it can be a lot of work.

You know, it can be quite a lot of, toll on a person to be a that key caregiver. And so, you know, understanding that research is the key to making a lot of things better, you know, understanding the situation, understanding what helps with the situation, understanding just, you know, different aspects, can lead to new solutions and new, you know, new sources of support for people.

And the same is true for caregivers. So there are some research studies that focus on the needs of caregivers or the, you know, the day to day stresses or burdens or also the positive experiences of being a caregiver, too.

but there's not that much. So, you know, we think there should be more there should be more focus given on the caregiving experience and more solutions and, services and programs available to caregivers.

And so that's why we established mass caregivers to support those kinds of researchers, research and the researchers that are doing those studies. And, it's caregivers also play an important role in research.

regarding the person with Ms. as well, they can be, sources of information about what they're seeing, that their person who has Ms. is going through or is able to do or not able to do.

So I confirm as caregivers is designed to support all those kinds of research. Now, Hollie I think there's probably, a lot of benefit for people with M. S.

and their families till the talk to peers. Yeah. So, MS In and caregiving peers is that something that people can do through I concur MS Do you have any kind of, peer to peer interaction or support group, conversations that occur?

We don't support, you know, regularly scheduled support groups and things like that. But, you know, our partner, MS Organizations, and there's many of them I could mention, do a wonderful job with that.

We do support interactions that have to do specifically with research. So we've convened, a number of advisory boards or focus groups for people with MS And, you know, we get great feedback from people that they find these really interesting.

They love to hear, their peers express, their, their opinions. And they also like to be able to share their opinions themselves. we also have the ride council, which you mentioned earlier, which is the research, inclusion, diversity and equity Council.

And this is a group of about 30 people with Ms. coming from different underserved or underrepresented backgrounds. They could be racial or ethnic minorities.

they could be people living in rural locations, veterans, people with disabilities. Again, you know, there's many different conditions that cause people historically from being excluded from research.

And we want to bring them together and hear from them directly about, how can research better include them? How can research better serve the needs of these communities?

And so this council has been meeting together for on a monthly basis for two years now. And so that is provided, a lot of great opportunities to, for them to get together, for us to learn from them, to get their advice on how I concur, MS Can better support, different underserved communities, but then also to bring them together with researchers like yourself.

Research Inclusion, Rural Access, and Closing Remarks

and, you know, our members really enjoy talking with you about your diet studies and hearing more about, you know, why you're looking into this and also providing feedback on, for example, a how can, you know, people in a certain culture with certain dietary traditions, adapt that to a specific dietary plan.

So or how can people who live far away from a research site and say, Iowa, be supported in, coming to, the study visits? So, it's the right council has been another way for people to come together on a regular basis and, and share their, ideas and their experiences.

Yeah. I do want to comment, Hollie, that, we did a study of rural versus urban care for MS and we were looking, and we so we did a survey based study that we did interviews, and we're analyzing the interviews.

We are presenting that research, we presented at the American school year and treatment and research and MS And, now we just submitted abstracts, I discussed that at the consortium MS Centers.

And there is a difference between the rural MS. and the urban MS experience. and of course, being in Iowa, I'm not at all surprised that there is a difference because it is much harder to get access to MS Specialist in rural Iowa than it is in urban Iowa.

and so, yes, I think it's very helpful for investigators to look at, some of these questions. well, I love what you're doing. I love the opportunity to come speak.

And I'm going to talk with you about coming back because we're still recruiting. So let's have another chance to tell people about our research. Invite them, to come.

Yeah. So one more time, Hollie how do people find you? So again, iconquerms.org I C O N Q U E R M S.org is the best way to find us. There's a contact us button.

There's a join us button. So if you have any questions. please contact us and let us know. And if you'd like to get involved. It's pretty simple. You just need to provide your email address and then, come to the site and see what there is to do.

And, and we also, send out opportunities for other research studies that are happening on a pretty frequent basis. So, you can do real MS And then you can also just, you know, keep an eye on your inbox for future opportunities of different kinds of studies.

There's a lot going on. And one of our goals is to get everybody who's interested in research connected with something that interests them. Great. Thank you so much, Hollie I really appreciate your joining us for, the MS Summit.

Thank you for having me. It is really a pleasure to speak with you.