INside the OUTcomes: A Rehabilitation Research Podcast

Episode 19: The Shirley Ryan AbilityLab Clinical Research Registry

SHARON PARMET: HOST

Welcome to INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is produced by the Center for Rehabilitation Outcomes Research at Shirley Ryan AbilityLab. I'm your host, Sharon Parmet. Today, my guest is Carolyn Ostrowski, the Clinical Research Registry coordinator at Shirley Ryan AbilityLab. Carolyn has the very important job of managing a large registry of research opportunities and spearheading efforts to recruit people to join the registry. Carolyn is a practicing physical therapist with more than 25 years of experience and brings that clinical knowledge to her role. Before we get started, I just want to give the Clinical Research Registry website. It’s [sralab.org/CRR](https://www.sralab.org/CRR). Welcome to the podcast, Carolyn.

CAROLYN OSTROWSKI:

Thank you, Sharon, so much for having me. I appreciate it.

SHARON:

So I guess we should start with the main question here. Can you just define and describe the Clinical Research Registry at Shirley Ryan AbilityLab?

CAROLYN:

Sure. The Clinical Research Registry or sometimes will refer to it as the CRR, is a nonpublic database in which researchers only from Shirley Ryan and Northwestern can utilize this database for recruitment regarding their rehabilitation related studies.

SHARON:

So what kind of conditions are in the database?

CAROLYN:

The research registry has a multitude of diagnoses. When I started with Shirley Ryan AbilityLab, we only were incorporating those individuals who had a history of stroke and spinal cord injuries. And then over the past four years, it's expanded to include individuals that have a history of cerebral palsy, non-traumatic and traumatic brain injuries, amputation, limb loss, Parkinson's and movement disorders, multiple sclerosis, ALS, cancer, musculoskeletal conditions like osteoarthritis, rheumatoid arthritis, or even bone fractures. In addition to our most recent, additions to the registry, which includes those individuals who have a history of cardiac and pulmonary conditions, and also individuals who maybe have a history of multiple diagnoses because they might have had a history of a spinal cord injury and had a stroke also to that they'd like to be involved in rehabilitation research.

SHARON:

When you register, you're registering by throwing your hat in the ring and saying, I'm ready to do a research project. And then what happens is that researchers who are doing projects related to all kinds of different rehabilitation topics can then call those people up and see if they want to participate in research. Is that right?

CAROLYN:

Yeah, definitely. So basically my role, and you've kind of summarized it in a way, but I'll expand a little bit on it, is to facilitate that connection of participants that are interested in being involved in research with research opportunities. So that connection, which is very difficult because before all of this and a lot of, you know, former patients at other institutions also, never even knew about research opportunities. So what we do is we provide information about our clinical studies and trials that are occurring at both institutions, connect those individuals with those researchers that are looking for those potential participants that meet their inclusion criteria of their study, and then those labs will directly reach out to that participant, tell them about the study, and then, you know, they can ask all the questions that they want to at that time, in addition to, if they're not interested in being involved in the research opportunity, they just say no, and that's okay. And other researchers will then call them in the future.

SHARON:

So when you register in the registry, what kinds of information are you giving?

CAROLYN:

Sure. I always want to assure potential participants that they just need to provide what information that they're comfortable with. So if we might ask them a question about a past medical history question, and they don't want to share that information, that's okay. But what we do try to obtain is basic demographic information, meaning a phone number and email address, or, you know, a physical address of where we can reach out to them. And then we'll ask them a few questions about some past medical history, because this can help our research teams, you know, contact them because they might meet the inclusion criteria of maybe a potential upcoming study. And then also we'll ask them about their current functionality, because we want to see how they're doing right in the here and now. And that might change over time. And that's okay. They're always given the ability to contact me in the future, and I can update this information so that they might fall under the criteria of a study as they move forward with their current therapies that they're ongoing with.

SHARON:

So, Caroline, you've talked about several different diagnoses, that researchers at Shirley Ryan AbilityLab and Northwestern are looking for to participate in a plethora of different research opportunities. But a lot of these research require people without one of these diagnoses to serve as kind of a control group. Can you talk a little bit about that?

CAROLYN:

Yes, definitely. Sharon, we've got, a, registry that's called the Non-Patient Research Registry. And as you mentioned, it's for individuals that do not have those specific diagnoses, that were mentioned earlier, and that want to participate in research projects that occur at Shirley Ryan. Or they can also, as we mentioned, a lot of our research that we do don't does not require them to come in person. So they might reach out to the individual to fill out a survey, or they might reach out to the individual to, you know, do an online interview. So this is a self-enrollment database and it takes less than five minutes I think. Really Sharon, it takes less than three minutes to be honest with you. And so what the individual is just asked is some basic questions. How do we get A hold of you by phone, email, texting? What's the best way to reach you? We'll ask a few questions about some past medical history, just so that we make sure that you aren't accidentally filling out the wrong research opportunity. And that's it. And then you'll automatically go into our database. Now understand also to it would only be research team members that are looking for healthy controls at Shirley Ryan or with Northwestern. So again, our Non-Patient Research Registry is a nonpublic database. So if you're interested in enrolling I have my son enrolled I'm enrolled Sharon. So it's a good way to also help our research teams at Shirley Ryan and Northwestern recruit for potential studies.

SHARON:

So when someone registers, is it safe to say they should expect a phone call or an email reaching out to them within a couple of months, or a couple of weeks, or it's just totally different for each type of study?

CAROLYN:

It can be different for each type of study, and it's based upon our research that is ongoing at the time at Shirley Ryan or at Northwestern. So we could have a lot of individuals, scientists that are involved in stroke studies that are looking for participants and they don't always have to be local. Also, to those individuals could be involved in research projects that live on the other side of the United States. They could be reached out within a month after registering or they can be reached out within three months. And some of that can depend on when they might have been diagnosed. Also, too, because our research teams might be looking for individuals that are maybe six months post spinal cord injury or a year post stroke. So again, they could be looking for individuals that are in the acute or subacute stages or chronic stages.

SHARON:

Right. And you said that you don't need to be living in Chicago to participate in a lot of these studies?

CAROLYN:

You're absolutely right. Individuals that are currently enrolled in our database, are local individuals that are maybe in the Chicagoland area. But again, we have people reaching out to us from all parts of the United States and all parts of the world, actually, because a number of our studies are on different social media platforms and people from other countries are looking potentially to be involved in, let's say, a traumatic brain injury study or a spinal cord injury study, that they might not have that opportunity in the area where they live in. They will then reach out to me, enroll on our online, website, and then provide me with a little bit of contact information or even email me to, and then we can schedule a zoom interview for those individuals that are not local.

SHARON:

Wonderful. Can you give a couple of examples of research projects that are active right now that people in the registry may, may hear about?

CAROLYN:

Sure. I'll kind of touch base on a few of our most prominent studies that individuals have reached out to me for additional information.

So one of the, studies that really piqued a lot of interest in the spinal cord injury population of patients is, of course, our NVG-291 study. This is where NerveGen Pharma has teamed up with Dr. Monica Perez to examine how the study drug and NVG-291, which is a therapeutic peptide drug that was developed to treat nervous system injuries and diseases and how the effects of NVG, how it affects the nerve connections in the spinal cord. So these participants would receive a daily injection, but also rehabilitation related training. So if, the individual is willing to stay with us, this is, I believe, a little more lengthy of a trial than we normally see, but I believe it's, 12 or 16 week trial that takes place on site at Shirley Ryan. This is one of the ones that has really, sparked a lot of interest, for participants that are in the registry.

Another really interesting trial, actually, which is through our CBMD, which is the Center for Bionic Medicine Department. And so those individuals who have had an above knee amputation, and what it is, is a microprocessor knee, also a powered ankle and foot. And they train those individuals that might meet the criteria of that study over a period of six months with a specialized prosthetic. And that's a really exciting study that our CBMD department is involved in.

And then the last one, Sharon, I wanted to kind of touch base on is from Dr. Jose Pons, is a study, which he is the Scientific Chair for Legs + Walking Lab, he has a stroke study which looks at the movement of hip and knee and ankle joints while wearing a lower limb exoskeleton. And as we know, exoskeletons have been extremely effective for those individuals not only who have had a stroke, but also spinal cord injuries and that have decreased movement of their limb. And so this can help to assist, with, a leg or an arm that might be very, very weak. And to improve the overall quality of life and their functionality of that extremity. So that's an exciting study that they're involved in.

SHARON:

Right. Those three all sound really innovative. And they all sound like they would require some visits to the hospital. But like you said earlier, there's also tons of opportunity to participate in online studies or studies that involve answering survey questions or, being part of, advisory councils. Is that correct?

CAROLYN:

Oh, yes. Definitely. There are tons of studies that they're looking for, surveys being answered. You know, as we mentioned, maybe six months a year or even five years. In addition there are Zoom or virtual studies, remote studies. Now, these are really exciting. Sharon. And also, remote studies actually involve individuals that might have, let's say, had a history of a stroke that want to be involved in, maybe improving with their arm functionality and so, and the use of sensors. So what we would do is our research teams would reach out to the individual, tell them about the level of participation. Send them a package to their home. And actually the instructions of how to, you know, attach everything that's necessary and then given an exercise program or what they would need to do. And all this is recorded then remotely on what the individual is, involved with. So that's really exciting too. So there's a plethora of different studies, whether or not you'd like to come in person or, if you're willing to just participate from your home.

SHARON:

And like you said before, the data is just provided to Shirley Ryan and Northwestern researchers. It's not shared outside of those two institutions, right?

CAROLYN:

That is correct. The individual, when they're recruited for a specific study, their information is only gathered in our database, which is, electronic data capturing system. And so these researchers have to have an approved study through our institutional review board at Northwestern and ask for special permission to gain access. So, again, a lot of individuals are more willing to participate in a nonpublic database versus one that might be a national database sometimes.

SHARON:

So what would you say to someone who's considering joining the Clinical Research Registry, or who doesn't really know much about being a research participant? What would you say to them? What are the benefits to them? What are the benefits to the to research and to moving the field forward?

CAROLYN:

Oh, wow. There's you know, I think one of the biggest reasons why a lot of individuals get involved in research is not only to learn more about their existing diagnoses, because there's a lot of questions that are out there when you first become diagnosed with any certain condition, but also to they want to. I think one of the biggest reasons why people want to get involved in research is to help other individuals that have their same diagnoses. And I think that that's really important is that paying it forward, you know, if they can help someone else that has a history of a spinal cord injury or a stroke or whatever the condition might be, and how we can learn more about, you know, why, you know, Parkinson's, you're you know, the questions about, the unanswered question about MS, you know, if they can learn more about these conditions, they're more than happy to participate and answer any questions. About a research study. So I think that that's one of the biggest reasons why are two of the biggest reasons why people get involved in research, learning more about themselves, possibly improving their current condition. And then also, you know, for people to learn more about that specific diagnoses.

SHARON:

That's wonderful. Is there anything else you want to add?

CAROLYN:

You know, probably there's a couple little tidbits that I want to add. So thanks so much for asking that. One, important person that I'd like to highlight is Dr. Zev Rymer. Dr. Rymer, he was probably not just Dr. Perez, but also Dr. Rymer was one of the biggest reasons why it drew me to Shirley Ryan. Shirley Ryan, as hopefully most of you know, was formerly the Rehab Institute of Chicago. And Dr. Zev Rymer was one of our founding researchers at the institution. And he actually started the first research registry, where it was only for stroke and spinal cord injury participants. And, he has been an integral part of research at our institution. So, he continues to do research, collaborates on a lot of the, multi-site studies. And so I want to throw a little shout out to Dr. Rymer.

But one thing that I want to highlight, before I forget, is Shirley Ryan is an amazing institution for a lot of different reasons, but one of the biggest reasons is how it is collaborative. And what I mean by that is it is unlike any other rehabilitation hospital. One main reason is not only to improve, the rehab of the patient that's there. Okay. The focus, of course, is on the patient first. But also one of its main goals is to improve health care overall by using the scientific knowledge to develop new therapies and medical procedures. And that what makes us a translational hospital. So it sets us apart from other facilities because we're seeing clinicians, physicians, researchers and supportive staff working together for that common goal of improving the quality of life of patients. And so this is probably being a clinician in the field for as long as I have, and especially in rehab. Makes me really appreciate where I work at and what I do right now, because I know that what I'm doing is a small piece of the pie of what's being done at Shirley Ryan. So I'm very appreciative of being with you today, Sharon, and also being part of this initiative with the hospital.

SHARON:

This has been INside the OUTcomes: A Rehabilitation Research Podcast. This podcast is supported by the National Institute on Disability, Independent Living and Rehabilitation Research. This is your host, Sharon Parmet signing off.