



Kessler Foundation Podcast Transcript:

Andrea Trotta Gagliano On A First Look at TBI Research

Recorded March 2016 [Listen to it here.](#)

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ANDREA TROTTA
GAGLIANO

: 00:10

[music] I introduce myself, tell them that their loved one qualifies for this national project, and they consent with me over the phone and talk to me without ever meeting me, but that's how much they believe in the work that we're doing, and I take a lot of pride in that, that I'm their kind of first look at research, and they really believe in what we're doing.

JOAN BANKS-SMITH: 00:30

Welcome to our newest podcast series, "My Life As A Research Assistant". This series is brought to you by Kessler Foundation, where we are changing the lives of people with disabilities.

Research assistants are on the front lines of our research studies collecting data, conducting interviews, testing subjects, and are the face of Kessler Foundation to our research study participants. In 2020, Kessler Foundation was ranked among one of the Best Nonprofits to Work For and Best Places to Work in New Jersey!

Throughout this series, we'll meet up with research assistants from our mobility, spinal cord injury, stroke, traumatic brain injury, and neuro science and neuropsychology centers who have been with the foundation for over a year and some that are now sr. research assistants, nurses, MD/MS candidates, post docs, and those that entered into many more professions.

In this episode, we met with Andrea Trotta Gagliano. She is a senior research coordinator in the Center for Traumatic Brain Injury Research at Kessler Foundation. She has worked at the foundation since 2012 and is also a licensed professional counselor on several current TBI protocols. Her main responsibilities are inpatient recruitment for two national projects, along with data collection and management and administration of clinical assessments and interventions. She also volunteers as a facilitator for a BIANJ-sponsored brain injury support group where she provides psychological and psychoeducational support for survivors of brain injury and their caregivers. Let's listen in. On a day-to-day basis, can you just give us an idea of what you do?

GAGLIANO: 02:19

I'm on a couple of our inpatient projects, the TBI Model Systems that we do in conjunction with the Kessler Institute. I'm on that, and I'm also on the Traumatic Brain Injury Quality of Life, which is also an inpatient project. So day to day, I am in charge



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of doing chart reviews for patients that are admitted into Kessler Institute at all three campuses. Of course, I have a coworker, Christian. We're on that section. We review the charts. So Saddle Brook, Chester, and West Orange campus, we're reviewing patients for eligibility for the TBI Model System, so a clinical chart review, and so from there, once somebody's eligible, we're working with the patients and the families to consent them into Model Systems. So those are the two inpatient projects. And then, with Dr. Kirk, I'm on a improving caregiver quality of life study. So what we're trying to do there is assess and also improve caregiver emotional quality of life, so individuals who are caregivers to a survivor of a traumatic brain injury.

- BANKS-SMITH: 03:25 And that's really important.
- GAGLIANO: 03:27 Very important, yeah.
- BANKS-SMITH: 03:28 Unfortunately, we look at the person that's been injured, but we don't take into account the caregiver and what that means.
- GAGLIANO: 03:38 Exactly.
- BANKS-SMITH: 03:39 It's not just bringing them to the hospital for rehab. It's all the behind the scenes.
- GAGLIANO: 03:44 It's behind the scenes, every single day--
- BANKS-SMITH: 03:45 And it's--
- GAGLIANO: 03:45 --24/7.
- BANKS-SMITH: 03:46 Yeah. And it really takes a toll on the caregiver and the family.
- GAGLIANO: 03:51 That's one of the main things we talk about with their caregivers initially, and why we're doing the project is, for the survivor, it's all about their quality of life, as it should be. But like you just said, behind the scenes, there's a whole support system that their life has been changed dramatically from the brain injury as well. So the first thing we say is, "We want to know about your quality of life and help you out and give you supports and resources that you may need," so yeah.
- BANKS-SMITH: 04:18 Yeah. That's really important. Does a particular research participant come to mind?
- GAGLIANO: 04:24 Oh, man. I've had a lot over the years. I have to tell you, I don't have one in particular that I could say has completely changed-- it's really every single day, I'm more and more surprised at how open people are, especially from both projects. So from the inpatient side, everyone is so much more open than I ever thought they would be, especially people that I'm cold calling, that I haven't met before, especially from Chester, Saddle Brook. And I introduce myself, tell them that their loved one qualifies for this national project, and they consent with me over the phone and talk to me, without ever meeting me. But that's how much they believe in the work that we're doing, and I take a lot of pride in that, that I'm their kind of first look at research, and they really believe in what we're doing. And so I'm so surprised, every single day, how



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open people are just to that in general. And then, from the caregiver side, ever since I started this project with Dr. Kirk, two years ago, I have never looked at brain injury the same. It's one way to see it when you're working with a survivor, but these caregivers, what they go through on a daily basis-- people have been struggling for years. And the fact that they still get out of bed every day and do it every single day, over and over, it's amazing to me. I am absolutely in awe of everything that they've done. And they too, they are even more open because they want to help caregivers in the future. They are way more passionate than any other participant I've ever worked with. So they make me look at life very differently, a totally different perspective on just appreciating everything we have and also the work that we're doing here. We also really do need to focus a lot on the caregivers. Yeah. Absolutely.

BANKS-SMITH: 06:15

It's really important that we have research participants, whether they're somebody who has a traumatic brain injury, a spinal cord injury, or a caregiver. What would you say to somebody who was on the fence about becoming a participant?

GAGLIANO: 06:29

That's a really good question. I feel like I have to do this spiel a lot because, especially on an inpatient level, 9 times out of 10, when I go into the room to introduce the national project, the Model System, no one has ever been a part of research, let alone works in research. I know for us, we kind of take it for granted because that's our everyday life, but really, I take a lot of pride in my job on the inpatient level because my face and the words that I use in our first impression is their first look at research. So when people are kind of on the fence about it, first of all, I feel like I explain things in layman's terms that don't kind of overwhelm them with legal stuff. But at the same time, I feel like when I explain to them the benefits of that project, it's about paying it forward. It's about the person that's going to be in this room years from now.

GAGLIANO: 07:43

And the Model System's been going since the late '80s, so it's the biggest well-rooted brain injury study on record, and so I can say, "This is what we've learned so far." I also use the Model Systems Knowledge Translation Center. I don't know if you're familiar with it. That's what all this research is going to, and that's our research translated into resources, I should say, and facts and figures for them. And so when I show them that, they're like, "Oh my gosh." I can just see kind of the light bulb go off that this is much bigger than them and that they can contribute. I also kind of take advantage of the fact that when you're affected by something in your life, you kind of want to give towards that, whether it is an injury or anyone that you know that's afflicted by X, Y, and Z. You kind of want to give towards that cause. And I feel like once people have been through that, they are like, "Okay. Yeah. This is a--" especially from the Model Systems' perspective, it's a big deal. And they can contribute, like I said, towards the greater cause. So like I said, people are usually pretty open, but that's kind of what I use, yeah, to move forward with their participation and to kind of encourage it. Yeah.



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- BANKS-SMITH: 08:50 Is there anything that you would like to share with us about your work here at the Kessler Foundation? I mean, obviously your passion about what you do-- and it's, "Open your eyes."
- GAGLIANO: 08:49 Absolutely.
- BANKS-SMITH: 08:01 Now, has that helped in moving forward with getting nationally certified, getting your state license?
- GAGLIANO: 08:57 I think so, absolutely. The certification I had, coming into the job, and I think that just kind of helped me understand the realm of rehab. I wasn't blind to that, coming into this job, which I'm really grateful for. I had other experience before, so I wasn't completely naive, which is good. But the licensures-- means a lot to me, absolutely. And I think that, especially with the caregiver project, that's where I'm going to be able to-- that's where I am using it the most. But having my counseling background and going through supervision with Antony, I'm just learning so much how to help people more, more, and more, every single week. And that way I can make our individual sessions better. I can make our support groups even better for the caregivers, and you have to go in completely open. When the caregivers finish their treatment, we ask, "Would you like a debriefing questionnaire?" And it's optional, but we want the good, bad, and ugly feedback of our support groups, and I want to know how I'm doing, individual counseling [and a?] group. And you have to be really open and really just let people give you constructive criticism. And as hard as that can be, it's sad, but I'm kind of used to it by now because between supervision and then what the caregivers themselves tell me about my counseling skills, it's only going to make me a better counselor moving forward. So yes, absolutely. My work here has really motivated me in terms of the licensure and moving forward, and I think that's so exciting because we have a couple of caregiver studies now, but they're both pilot. Or one's pilot, and one we're doing with the University of Michigan. But that's so new for us in the lab, so I just think that we're just planting the seed for future caregiver research, which is really, really exciting, so.
- BANKS-SMITH: 10:48 I just want to thank you for spending a few moments with us.
- GAGLIANO: 10:51 Thank you. I appreciate it. [music]
- BANKS-SMITH: 10:53 For more information about Andrea, Kessler Foundation, and how to become a research participant, be sure and check out the program notes for this podcast. Tuned into our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. Listen on iTunes, SoundCloud, Spotify, or wherever you get your podcasts. This podcast was recorded on Thursday, March 31st, 2016, at 300 Executive Drive, West Orange, New Jersey and was edited and produced by Joan Banks-Smith, creative producer for Kessler Foundation.