KESSLER FOUNDATION Podcast Transcript

2023 Spring Brainstorm - Transition to the World After Brain Injury

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JEAN LENGENFELDER: 00:06	[music] Welcome to our quarterly virtual speaker series, Spring Brainstorm. This series is sponsored by the Kessler Foundation as part of our TBI Model System Grant, which is funded by the National Institute on Disability. Independent Living and Rehabilitation Research. Today's presentation is by Mike at the Mic and titled Transition to the World after Brain Injury. It is now my pleasure to introduce Michael Greenwald. Mr. Greenwald has been an integral part of the Brain Injury Alliance of New Jersey since 1992. A retired teacher, Mr. Greenwald currently serves as an officer on the alliance's board of trustees. He has been a support group leader for over 25 years and was a strong force in establishing the council for the head injury community, now known as Voices Advancing the Brain Injury Community. Voices' mission is to champion and publicize the advocacy rights and needs of people who have survived a brain injury. Mr. Greenwald is the creator of Mike at the Mic, a panel discussion of topics related to brain injury that has become one of the signature events at the alliance. Welcome, Mike.
MICHAEL GREENWALD: 01:32	Thank you so much. We're going to be talking today about a transition to the world after brain injury. We have a few objectives: first, to learn of the challenges that people with brain injury face when transitioning into the world after sustaining a brain injury; second, to seek out how people with brain injury have endeavored to address the challenges that they have while transitioning into the world; and finally, to define what services and supports are helpful to people with brain injury as they transition into the world. We have a number of fantastic panel members, and I'd first like to introduce, Sharon [Nutty?]. Sharon.
SHARON NAULTY: 02:28	Hi, my name is Sharon Naulty and I sustained a brain injury back in 2011 and finally diagnosed back in 2016 and have moved forward into a new life. I'm here as an advocate, and this has been one of the joys of receiving a brain injury, although I'm not going to say I would recommend it. But there are upsides to it, and that is there are people and places and therapies and treatments. And it's a very sharing community where you find a voice. And the doctors will speak with you. The scientists. It's an ever-changing field. I have memory issues. I have aphasia. I have multiple issues, but if you looked at me, you would think that I did not have an injury. And I think that's probably one of the most frustrating things for everyone that's here on this panel. But we do have a voice. We have Dr. Google, and then there's the iPhone, which tells you where to go and how to get there. So I'm grateful for that. So better to have a brain injury in 2020 than 1980, for sure. So that's a little bit about me.
GREENWALD: 03:47	Thank you so much, Sharon. Our next panel member is Scott Pullman. Scott, good morning.

SCOTT PULLMAN: 03:54	Thank you, Mike. Hello, everyone. So my story, as quickly as I could tell it, is this. About six weeks after my 40th birthday, in the summer of 2017, I was living in Los Angeles, feeling as optimistic about life as ever. There's a saying, "Life begins at 40," and that was true for me but just not in the way I was expecting. I came down with a bad case of pneumonia, which I suspect I caught while spending a weekend right on the border of Mexico. I wasn't doing anything scandalous. I was just in a place where my immune system just couldn't handle. I got back to LA, told a doctor this. He didn't listen to me and dismissively sent me home, which gave me a very uneasy feeling at the time. But my nightmare had just begun, because the next day I collapsed in my apartment and hit my head on something. I say, quote, "something" because I can't remember the incident at all. But when I regained consciousness and called 911, I knew my life would never be the same. I did have a little bit of experience with someone with a brain injury because my niece had come down with an acquired brain injury a couple of years before my accident. So it goes without saying, this was a rough stretch for my family, which knew its fair share of rough stretches. But the good news is, as we'll explore in this Zoom meeting, I was able to bounce back eventually with the help of the Brain Injury Alliance, Kessler, and a few other organizations. It wasn't easy, to put it mildly, but with the help of all the professionals, family, friends, organizations, I've been able to rebuild my life. And in certain respects - not all but some, as Sharon alluded to - my life is actually better than I could have imagined, even before my life changing injury. I've been living in New Jersey ever since, being near my family. I've made a lot of new friends, and I've enjoyed life a lot more than I ever thought I could.
GREENWALD: 05:32	Thanks so much, Scott. It's good having you on our panel.
PULLMAN: 05:36	Good to hear, Mike. Thanks.
GREENWALD: 05:37	Our final panel member is Patty Thompson. Patty.
PATTY THOMPSON: 05:41	Thank you everybody. Thank you. Good afternoon. Thank you, Tom and Mike and the panel speakers and Kessler and the Brain Injury Alliance for allowing this service to happen. I am a brain injury survivor of nine years. My incident occurred in 2014. It was a work-related injury. I was a 25-year veteran critical care nurse. At the time, I was 47 years old, a single mother of two children, two teenage children. And I knew, when I hit my head, that was the worst pain that I had ever encountered. It was beyond anything. I lost vision in my eye, my hearing, tinnitus, everything. The whole onslaught of post-concussion syndrome occurred to me over time. It was very insidious. I am grateful to the Brain Injury Alliance and my case manager, Deborah, who I credit for saving my life at the time, for helping me navigate this world of brain injury in receiving assistance in therapies and supportive services, social services as well. I did, in 2018, have sustained the loss of my 18-year-old daughter due to a massive head injury. And my 16 year-- well, my 21-year-old son now is doing fantastic. But I did lose my job. I lost my place. I lost myself. I lost so much in this incident. And I find myself crawling out of the hole of despair, trying to bring light and guidance forth to those who are suffering now and to help navigate that path moving forward. And

I'm in the infancy of my advocacy. I have-- joining Voices group. And I'm a member of the State Board of TBI Survivors Council in effort to provide insight where the gaps are. And my goal is to advocate by creating a positive change and awareness to the needs and cares of the current and future TBI survivors and their caregivers.

GREENWALD: 07:38 Thank you so much, Patty.

THOMPSON: 07:41 Thank you, Mike.

GREENWALD: 07:41 We would like to get started. Most of our questions basically come from the audience, and I realize that we have a nice audience out there, so please think of good questions. We have a fantastic panel right now. I'll ask the first question. I'll ask it to a panel member, and if any of the other panel members want to comment, that would be most appreciative. And if anybody from the audience would like to comment, that would also help. But I expect the audience to be asking most of the question. First question that I have, I'll ask-- for Sharon. Sharon, how do you explain your predicament to outsiders?

NAULTY: 08:32 That's a good question, Mike. I tend not to explain. I try and navigate as much as I can without telling someone what's wrong. However, I do tell people. In situations where things are confusing and I have to ask questions, I will say just bluntly, "I have a traumatic brain injury," and then everybody slows down and is more helpful. In regards to helping with others in the community, just in the outside world, it has been difficult for me to navigate. I have found that people don't understand it. And the support groups from the Brain Injury Alliance, my therapies, being in that like-minded community is really what has helped me get through. So that's not a great answer, but I'm still looking for answers on that too. I don't think I've figured it out yet. And it's been 11 years, and I still haven't figured that one out.

GREENWALD: 09:35 Would anyone like to comment on that one? How do you explain your predicament?

PULLMAN: 09:42 Well, first of all, Sharon, you did just fine. I do think that-- not just my own situation and Sharon's and Patty's and everyone else. But I think a lot of people know, especially if you follow American football, that 11, 12 years ago, suddenly, concussions came to the forefront, and they gained a lot more attention. And I could just kind of remember thinking-- I mean, you sort of know in the back of your head, no pun intended, that, "Yeah, concussion. That sounds bad." You get a little bit dizzy; maybe you get more dizzy. Your head hurts. But it never really occurred to me that this is who you are. Your head is who you are. Your body and all the rest of it is just an illusion. Your spirituality or lack of spirituality, whatever it is, everything comes from here. When you think, "Boy, I'm hungry." It comes from the top of your head. When you get hit there, it's affecting you, your whole essence. So I don't actually know-- I know that my hit was bad. It wasn't nearly as bad as a lot of people. But suddenly, all the signals that had been going on in my brain from literally as far back as I could remember to the incident, they got rerouted somehow. And it was like I couldn't

	follow the directions that they were going, and I couldn't process the information coming in.
PULLMAN: 11:04	But there were two things that would drive me crazy. One, like Sharon was saying, you look at me kind of like, "Well, well, you look fine," other than looking at the giant gash in the top of my head, which most people couldn't see anyway. It was sort of in my blind spot. But outside of that, it's like, "You're walking. You're talking. What's the big deal? Just relax. Take it easy. Don't panic". And then the other thing was-- oh, I lost my train of thought. [laughter] Maybe that's a side effect. I don't know. But I think that it's just being able to express, "Look, something's wrong," even though there's nothing overtly on the outside of who I am, just the way that I'm operating. I can't operate in a normal way. And so you just kind of have to be patient. And you have to kind of understand other people's ignorance, remember my own experience before I had a brain injury, and just sort of transpose it onto them and just stick with it. And most people I found are patient enough to listen. And the more I advocated for myself, the-- I won't say easy. It didn't get easy, but I found-- especially living in New Jersey, finding all you nice people out there in Kessler and Brain Injury Alliance, it helped in that way. So you just have to-- you have to be patient, stick with it, and just advocate for yourself as much as possible, and try to forgive people for their ignorance.
GREENWALD: 12:24	Thanks Scott.
THOMAS: 12:26	Hey, this is Thomas. May I speak?
GREENWALD: 12:29	Sure.
THOMAS: 12:30	Sharon and Scott, those were great. Sharon, I really relate to you because I still, after three years-- I've had it for many, many, many years, but after three years, I've started doing my business again. I'm a scientist, and I found the less they know about me, the better. But there is a time-- I may go a half an hour. I may go two and a half hours, but there is a time the old brain just says, "I've had enough." And you got to either tell them what's wrong or you got to leave. So I really appreciate your introduction of how you deal with life. I mean, it just-- not carbon copy, but very much. One other thing I'd like to ask is, [Mike at the Mic?], was that a program you folks have?
GREENWALD: 13:19	No, we don't. As a matter of fact, we run our program similar to the way-- you might remember this. I didn't get your name sir, though.
THOMAS: 13:29	Thomas.
GREENWALD: 13:30	Thomas, I developed this whole concept, Mike at the Mic, based on the way that Phil Donahue used to run his show, and that's what he did. He had a panel. And then based on the panel, the audience asked questions. And by the way, if our panel hadn't taught, you wouldn't be asking your question right now, Thomas. And I give you a lot of credit. By the way, I was a science teacher. What kind of scientist are you?

THOMAS: 14:02 Microbiology. And I have my own inventions, which caused my TBI. My partners thought they could seal it from me, and they weren't successful in getting rid of me, so I survived. But enough of that. I just want to thank Sharon very much. I mean, it's just so much what I go through every day. And I have two more meetings where I need to participate today, which is one more than I should tolerate. But when you're doing business, sometimes you got to suck it up. I just hope I can. But thank you, Sharon And thank you, Mike, and everybody else here. I love this organization, and I appreciate your encouragement when you talk truthfully. Truthfully is the most important thing; second is forgiveness.

GREENWALD: 14:54 That's our intention. [laughter]

LENGENFELDER: 14:59 Mike, I see that Peter has his hand raised.

GREENWALD: 15:02 Peter--

PETER: 15:02 Hi.

GREENWALD: 15:02 --would like to say something?

PETER: 15:04 Oh, yeah. I want to get in touch with Thomas. I'm a retired neuroscientist myself. And getting back into science is something that I tried to do, but I kind of found that-- I guess I was dismissed a little bit. Of course, it was several years after my accident that I was able to start to look for work. And now, expanding on something Sharon said, something Scott said, Patty and Thomas altogether, getting back into society, regaining your life and things. Sharon talked about decisions on whether to disclose her condition. And what have you found - I guess the person from Kessler could weigh in in this as well - talking to a prospective employer? And how to navigate that situation where you're talking about kind of an unpredictable [crosstalk]--

GREENWALD: 16:11 Well, what do you feel is important? As a matter of fact, that's a good idea. In talking to a future employer, what do you feel is important that you disclose?

PETER: 16:24 Well, it would depend on any difficulty you might have: movement difficulty, attention, things-- some of these things will stick in the mind of somebody interviewing you and thinking, "Wow, no, we can't really have that, so I'm going to think of a business reason to decline their employment." How do we defend against that and advocate for ourselves well enough to be given a chance?

GREENWALD: 16:54 Sharon?

NAULTY: 16:55 So I'd like to interject in there. I used to be an executive recruiter, and I hired people for 20 years and had a business with a partner. And so I have taught career strategies, courses, etc. And I think it goes back to, when we're looking for a position-- and not that I've done it wonderfully, but it is all about networking. And it is about-- and it's different. There is the Americans with Disabilities Act, and there are legal ways that you can ask your case manager what is allowed to be said and what is allowed not to be said and what are discrimination practices, etc. But it is about getting together, meeting people, and doing career advancement through networking and finding out where the positions are. It's doing your own research. And so therefore, you're not going into a situation blind. So you don't have to disclose that information upfront because it puts you in a bad perspective, and it might make the interviewer uncomfortable. But you can make it work, and it's through all the things that you do sideways. Does that make sense? You're not going right through the front door, but you're having other people that you know that know your strengths, your weaknesses, can give you information, and you kind of go in the side door.

PETER: 18:23 Yeah. So you mentioned using--

NAULTY: 18:24 That is the only way I think that it works.

PETER: 18:26 Yeah. So you mentioned using your network to find people who may be more willing to give you a chance. And part of the reason I asked my question about employment is I'm participating in a Kessler research study about training a person's competence in a job interview situation. So it's been interesting experience so far. I'm about halfway through it. And yeah, it's been a learning process, even though I'm 58 years old. Having worked in a number of different scenarios--

GREENWALD: 19:02 It does not mean a thing.

PETER: 19:04 Yeah. What I'm saying though is, the experience I had over decades of a working life, I'm now back at the point where I need some help in figuring out how to present myself. So Kessler is at least trying to address that. So ask them about this study, if there are any more openings for it.

LENGENFELDER: 19:24 Mike, I think Albert has his hand up for a question.

GREENWALD: 19:28 Albert, would you like to chime in?

ALBERT: 19:30 Thank you. I'm a licensed clinical social worker. I had to work really, really hard to get a license. We're in really high demand right now. I work for Navy Medicine for 10 years. I worked up at Camp Pendleton. And one of the things I learned about TBIs is there's a correlation between that and suicide. And I had a friend, his skull was smashed in, and he ended up committing suicide years later. My history goes back when I was an infant. I was dropped on my head. I have bumps on my skull. When I was 14, I went through a windshield of a car. And about 40 years ago, I had a stroke. I've been in different studies at UCSG. Nobody told me about my brain damage until just a couple years ago, when I actually saw the area of my brain from an MRI that was damaged.

ALBERT: 20:23 I did know that after my auto accident, in hindsight, I was a very angry person. One of the things I learned about-- what gives me resilience is groups. I joined Recovery International because they really help you with grappling with temper. So I'm brain injured, and I'm an angry person, but I don't appear to be so because I have enough support to keep it under control. I also run a support group for the Leukemia and Lymphoma Society, and support groups really increase your social capital. And I just want to say one more thing about-- part of my success for employment is I focused on my passions about what I was passionate about. That's why I'm with LLS and with [KIDS?] from San Diego. I'm fake retired now. I'm 70 years old, and it's my passion that had gotten me the position. And companies that didn't appreciate my passion and weren't willing to accept me on my terms, well, it's good that I didn't end up with those people because it opened up the door for being in a place where I'm really doing what I really love doing. And I feel like I'm really making a difference, and I have a rich life.

PULLMAN: 21:37 That's very admirable, sir. And--

GREENWALD: 21:39 Thank you very much. We have, I know, a lot of fantastic people in our audience, and I thank you very much for chiming in because it's one thing that these sessions don't plan for. We don't have questions which are scheduled, and I'm the only one that has the questions that are going to be asked from me. However, there are other questions that you might have in the audience that you can ask any of our panel members. I'd like to ask this one from Patty. Patty, where do you see yourself if you can't go back to your old job?

THOMPSON: 22:23 I definitely could not return to my job. I became a liability.

GREENWALD: 22:27 What kind of job did you have?

THOMPSON: 22:29 I was a critical care nurse, neuro ICU nurse, coronary care nurse, for 25 years. Due to the injury, I lost my executive functioning, my rational thoughts, my emotional regulation. My personality changed. I felt like half of me died that day and this other self is emerging, but through that. And my situation was a single mother with no support. So my drive was to go back to work. I had to work. I didn't have an option. I don't have any other income. I tried, and it was a major failure for me. I just could not function in my job. I was not safe. I was a liability. I was vulnerable, and I was vulnerable to other injury as a result. I would like to speak to the point of people trying to return to work with light duty that there's no definition, no description of light duty coming from the workplace. And that needs to be defined for people with concussion trying to return to work. If they can't make accommodations in an environment, and the care and the stimulus for us, that we should not be returned to work on light duty. We should just be kept out of work, disability, or workman's comp, whatever. And I would like to see workman's comp acknowledge post-concussion syndrome as a chronic and debilitating disease and to satisfy reconciliation and payment for that.

THOMAS: 24:05 Thomas Quinlan. Can I comment?

GREENWALD: 24:07 Yes, sir.

THOMAS: 24:08 Patricia, that's beautiful. I just love being here today. So glad. What an encouragement. Can I make one comment for Peter Wick? What I had to do-- because in microbiology, you had a lot of big, long medical technical terms. Well, I had to downplay everything to third grade, man. [laughter] I couldn't pronounce the words that used to just spill out of my mouth. So the downsizing is very difficult, and I'm still working on it. And because of that, every once in a while in a presentation, I will completely go blank. I mean, absolutely blank out, because I cannot think of the word I want that would describe-- 15 minutes of description, because that's a challenge. When you're in the middle of a presentation or an interview and all of a sudden you go blank, you got to come up with something. Be prepared. I call it management. Be prepared to take care of problems. As you grow, you'll see all the problems you have. Try to premeditate. If I go blank in an interview, what am I going to do? I might say, "I'm sorry, I got to go to the bathroom real quick," and hopefully I can regain some foothold. If I can't, I'm just going to have to leave. That's all. Doesn't make me evil. Doesn't make me less of a human being. It makes me a human being that's trying to survive daily. So anyway, thanks for listening. And I consider it a complete honor and blessing to be with you guys today. Thank you so much.

GREENWALD: 25:46 Well, I thank you so much for attending, Thomas. It's really good having you.

THOMAS: 25:51 Yeah, it's good to be.

LENGENFELDER: 25:52 There's another question from the audience. Lauren has a question.

GREENWALD: 25:56 A lady. Lauren.

LAUREN: 25:58 Hi. I'm Lauren. I'm a research assistant in the Center for Traumatic Brain Injury Research at Kessler. So I just had a question for anyone who feels like answering. So what is one piece of an advice that you would give to yourself when you were newly injured, knowing all that you know now?

GREENWALD: 26:15 Any of our panel members like to take that one?

THOMPSON: 26:17 I'll take it. So definitely, if I could go back to become immediately engaged with the Brain Injury Alliance and support groups for concussion and to have the resources put forth-- which I feel is a big gap, from concussion, from diagnosis, and then treatment, because the doctors will say, "Oh, go back to work. You'll be fine," or "Just think you'll be fine and you'll be better," or "Go garden or do something." No, no, that doesn't work. The rehab needs to start immediately. The awareness of what's going on in your brain, to validate what's going on in your brain from somebody else, from a healthcare professional, and then to guide you through this is paramount. Definitely getting help straight away and keeping a journal, journaling your days, your feelings, your headaches, how you're feeling, and then keeping a schedule of events-- because, boy, does that slip through the cracks really quick? You can't keep track of anything or anybody. So definitely keeping a journal, getting involved with the Brain Injury Alliance or other support groups, concussion, whatever, definitely puts you, I think, in a better place to heal quicker.

GREENWALD: 27:31 Does anybody else on our panel have any comments? I know there are people in the audience that really would like to comment on that question.

PULLMAN: 27:41	I can add a couple of things because, for me, I was in a real panic, because one of the things I hated-- and I understand how people intended it. But even then, I understood it, but I hate when people say, "Oh, you just got this brain injury. You're new to this." It was almost a little bit dismissive. Whatever my panic was, it was like, "Relax. You just had your-- this just happened." So of course, you're going to be upset. And there's truth to that because there's certain things that, early on, coincidentally-- let me just share this real quick. I actually bumped my head just a little bit on a bus. I didn't see there was a metal beam above the seat. I was okay, but I was reminded-- for about 10 minutes, I was completely disoriented. And it was like, "Well, I've been through this before. Just relax. It was probably like 1% of 1% of my TBI." But just remembering that feeling of disorientation and that panic. So I think that when people panic right away, I'm not going to say calm down, but just understand what that is. Understand that that's a new feeling and articulate that you need help, but at the same time, understand that it's not-- certain things will get better. Some things didn't get better, but other things did. So after a day, a week, even a month, if you still have that feeling, just advocate for yourself, but don't think that it's permanent. There are ways around it. There are ways. There are help. So I think that's the one thing, instead of panicking so quickly. Knowing that there was hope, there were people who can help, I think I would've maybe felt a little bit less panic.
GREENWALD: 29:22	Thanks Scott.
LENGENFELDER: 29:23	Mike, Leannie has her hand raised.
LENGENFELDER: 29:27	Leanne. I had an acquired brain injury about nine years ago, and my experience was that it's one of these invisible brain injuries. I mean, there was a time when I couldn't really walk and my balance was way off and I had a lot of vestibular issues, and some of that remains. The vestibular is really the only thing that is physical that I deal with, for the most part. I thought I was going to be okay in like a couple months or something. I had no idea what had happened to me. I remember I was in an elevator at the hospital and somebody was just being friendly, somebody who worked at the hospital, and I said, "Oh, I had a hemorrhagic stroke," or whatever. And he's like, "Oh, you've just been handled--" he was being sympathetic, and he said, "You've been handled a big, difficult thing." And I was like, "Oh," because I didn't know anything about it. And I sort of look back at that as helpful because he was being very sweet and sympathetic, and I had no idea what was going on. And the doctors, as somebody mentioned-- I talked to my neurosurgeon, and I didn't actually have brain surgery. But I talked to him, and I said, "How long is this going to take to heal?" And this was like six months on. And he's like, "Well--" or four months maybe. And he said, "Well, that's six months." I said, "Well, it's been four." He's like, "Well, you had some difficulties, as I had with vestibular and stuff beforehand." But I realized afterwards, he was talking about something physical that really didn't have-- I mean, it did have a bearing on my life. But he was answering the question like, "When would I stop needing him?" I think, essentially.

LENGENFELDER: 31:27	All that evidence to say, "I had no idea what was going on." It wasn't really until someone told me about the support group at Kessler-- and I remember even having a conversation with her. I said, "Well, at the support group, there's probably going to be people in much worse shape than me. Maybe I don't really kind of deserve help because I seem to be kind of fine." And she's like, "No, you have a brain injury." So it was almost like I didn't know what was happening. And that was one of the hardest things because I thought I was going to go back to work. In a way, I'm glad that nobody came to me and said, "You've got this, this, and this," because for one reason, you can't really tell. It was very hard to kind of find where I was in space in terms of my life. And now I've forgotten what the question was, but I know that's what came to me when it was asked, that that was particularly difficult and that the support group was really helpful, and then just kind of hanging in there.
LENGENFELDER: 32:36	Peter also has a question.
PETER: 32:38	Not so much a question, but--
GREENWALD: 32:41	Comments?
PETER: 32:42	Yeah, it speaks to something Scott had said, as well as Leanne was just saying. I wish I had been more patient with myself. I was anxious to recover whatever it was I felt I had lost. My cognitive abilities weren't really good at that time. And I had been an athlete, so I had this Energy since I was released from the hospital. Within a month and rehab, I tried to do things that were not really safe, especially since my wife had to go back to work. There was some time that I was alone and-- yeah, it wasn't so smart of me. Of course, I didn't injure myself further, but looking back on it now, I wish I had been more patient. I wished I went a little slower. But at the time, there's no way I would've been able to listen to that at all. And then the other point I wanted to make was, "Yeah, a brain injury. It's unpredictable." So even that doctor giving the six months or so estimate, that's not true for everyone. It might be true for a subset of people, but some people take a lot longer. Some people recover much quicker. So it's really hard to give yourself a deadline for recovery. It's tough to struggle against that. It's easy for me to say that some nine years out from my accident, but I wish I had been more careful and more calm and deliberate in my recovery. But at the time, that wasn't possible.
GREENWALD: 34:19	Well, maybe people that are listening to this today might take your words and think, "Maybe there is something that I am going too fast with." Thing is that's the purpose of this. We want to get ideas out, ideas that people can relate to, because in the world of brain injury, there is not a lot of relationship unless the brain-injured patient hears other brain-injured patients, because most of the time the doctors push it off. Then--
NAULTY: 34:54	Mike. So when I was diagnosed, which was in 2016 or something to that effect, I then had treatment. And I had cognitive therapy with a neuropsychologist. And I had speech therapy. I think that's it, but that was a lot. And I think one of the things that I

felt-- although I went to a-- I loved my neuropsychologist, and we worked well together in her kindness and compassion so that I could be me with all my faults, as I called them. But it was not an acceptance. I didn't understand. I had no biology training, no neuroscience training, and so I didn't get it. And I didn't understand the body. And I think when I started to read everything that I could get my hands on-- Lisa Genova is a neuroscientist, and she's written a lot of books on different types of injuries, illnesses with brain injury, and I read all of her novels. And they were sort of based on science. I remember going to the New Jersey Brain Injury Associates conference. That was in May, and it was for their professionals. And I signed up. And I had this aha moment when I was in one. I had many aha moments that day.

NAULTY: 36:20 And I was listening to a neuro optometrist who was talking about problems. And I'm like, "I have 12 of the 15 symptoms for a vestibular disorder." And I remember going up to him afterwards and saying-- his name is Dr. Vicci, and he's well known. And he's worked with Kessler and at JFK. And I said to him, "Do you take new patients?" I introduced myself, and I think how funny this is. And I said, "Do you take new patients?" And he said, "Yes, but there's a list. But I'm happy to talk to you. I'm happy to help you." And I was so shocked by that, frankly, aghast that I as a patient, whom everyone-- my friends would say, "Oh, well, I can't remember that word too." And that is the most non-helpful thing to ever say to someone who's looking for a word because you're trying so hard. But this perfect stranger would say to me-- who had a tremendous amount of training and education and put all that work into it would say, "Sure, I'll help you. Call my office and let's schedule something." And I think we underestimate how much that means to all of us. Not every doctor's going to be that way.

NAULTY: 37:40 I remember the support group when I went from-- I was always a caregiver, and all of a sudden I had to become a survivor. And I had to talk about what my problems were, and I couldn't talk. And believe it or not-- and this woman - and I don't remember her name because I can't remember names - she was sitting sort of next to me. And she got out of her seat and came over and held my hand. And she said, "It's okay." And the tears were just coming down my face, and I was like, "I don't ever do this." And she said, "Well, it's about you now. You need to talk about you." And I think because it is the brain, it is the engine of our bodies, and it affects everything-- and it is fascinating. I mean, this is a fascinating trip, but giving that love and opening hearts, you gained so much. And you don't think you can ask those questions, but you can, and you will get further doing that. But it's a different place, and it's new. But I think what surprised me most was how giving the community was that has helped me get back on track to be the me again that I am and not feel like a sinking ship all the time.

GREENWALD: 39:13 One thing that we've noticed that brain-injured patients-- basically, I think when they get in contact with other brain-injured patients, they are very open, and I have never met any more caregiving people than brain-injured people discussing injury. And I've noticed it in my groups. I've noticed it in Voices. I've noticed it today with the couple of people that have been on. And that's why I enjoy this meeting, because this is where you are letting go. This is where you are describing and asking for help. And folks, if you don't ask, you don't get it, so.

LENGENFELDER: 40:10 Mike, it looks like Gina Marie has her hands up.

GREENWALD: 40:14 Okay, Gina Marie, how about this time?

GINA MARIE: 40:17 Okay. Hi everybody, and thank you again for having us. Thank you, Kessler, for continuing to be partner with us as a program and really support and just group hug us as we continue to live. There's a lot of great things that we said. Some things, I got triggered by. I don't remember everything that I wanted to say. I'm sorry. But one thing I did want to throw out there is it bothers me to hear people say, "Oh, the new me." Everybody lives on the new normal now. There's no such thing as a new anything. We're still us. I want you to embrace that and love yourself. There's going to be days where, yeah, you're going to be angry. Guess what? Everybody gets angry. Everybody has tears. Some people are going to tell you emotions are poopy-caca. But if you think about it, every life tragedy, like a passing away, they have this cycle that you go through. So who's to say that our cycles, just because we're not on the same timeline as supposedly these studies tell us to be, means that we're dysfunctioned or we're not healthy enough.

LENGENFELDER: 41:29 I want you to make sure that as much as it confuse you and you not remembers and you forget, and you have days where you're like, "All I do is fight, fight, fight," that you are valued, you are loved, that you need to continue and you are good enough where you function. Even if you fall flat on your face and you're like, "What the bleep? How'd I get down on the floor?" You are still worthy of respect, because I heard a lot of things being said, like, "How do you fight for this? And how do you express yourself?" I feel that our society has to box-label everything. And I think that we limit ourself too much to that because they have no idea how much power we have because we are still here. There's a purpose we're here, and I'm getting off track because-- I raised my hand because of something someone said, but I really appreciate the program. I love you guys despite some of you may loathe up on my wretched soul. But I want to send group hugs to you peoples and let you know that you inspire me, that you helped me fight on days where I just want to stop, because a lot of these programs and laws in place, it's very [moronoxy?] where you have to fight and continue. Thank you for listen to me and allow me to be part of your lives. I really appreciate [crosstalk].

GREENWALD: 43:05 Hey, Marie, thanks for being part of our conference today.

LENGENFELDER: 43:09 Mike, is there anything you would like to say to wrap up? Because we're nearing the end of our time now.

THOMAS: 43:16 This is Thomas. Can I speak for 30 seconds?

GREENWALD: 43:19 Go ahead, Thomas.

NAULTY: 43:20	I could not recover until I got away from a support group here in Colorado that is very detrimental. Has nothing to do with your group, but it took two years to get out of there. And when I stopped thinking in the new norm, I realized I had a permanent injury, and I started to manage it. And I'm really no better than I was 10 years ago, but I can manage it with skill. And this young lady who just got on there is absolutely encouraging. No, I'm Tom with a TBI. I am not a TBI Tom. I'm still Tom. Don't take that away from me with the new norm. I'm going to still be Tom. I just have a TBI. So I can't pronounce your name, sweetheart. [Gina Marie?], but thank you. What an encouragement you are.
GREENWALD: 44:12	Everybody. We have to stop soon, unfortunately, but if anybody would like to make a closing statement. Any of my panel?
THOMPSON: 44:22	Mike, we go through our lives, living our lives one way that we've accustomed to, and then one day it changes because of concussion head injury damage. And then we do follow a path of recovery. And in that time, it's a darkness. It's a fog, and we don't understand what's going on with ourselves. And to accept it seems unacceptable because your brain just cannot accept what happened to it. But I feel that when we come to terms with our abilities and our limitations and our disabilities, just coming to terms with it, understanding that we have good days, bad days, kind of helps us navigate this path, that we are not the same, where our essence is the same, some things change, but that we could jump off of that and continue our path onto healing. And with help, with therapies and stuff, and medication, definitely promotes a better outcome.
GREENWALD: 45:29	Thanks so much, Patty.
WEBER: 45:30	Yeah. Thank you for that wrap up, Patricia. We appreciate it. We want to thank Mike and all the panelists today and all the audience.
ANNOUNCER 45:41	Tuned into our podcast series lately? Join our listeners in 90 countries, who enjoy learning about the work of Kessler Foundation. Be sure and subscribe to our SoundCloud channel, Kessler Foundation, for more research updates. Follow us on Facebook, Twitter, and Instagram. Listen to us on Apple Podcast, Spotify, SoundCloud, or wherever you get your podcasts.