

Volunteering Has Given Us Both a Purpose - 2020 Brain Injury Alliance of New Jersey (BIANJ) honoree Jane and Joe Concato

Recorded April 2020 [Listen to it here.](#)

JOE CONCATO: 00:05 [music] We're happy to participate, share our opinions on items related to research, conferences, newsletters, to assist people impacted by brain injury.

ERICA WEBER: 00:16 I'm Dr. Erica Weber, a research scientist in the Center for Traumatic Brain Injury Research here at Kessler Foundation, and I'm joined today by Joe and Jane Concato. And we just wanted to, first, congratulate you on your award. You're Volunteer Service Champions by the BIANJ, so congratulations to you both.

JOE CONCATO: 00:35 Thank you.

JANE CONCATO: 00:36 Thank you.

ERICA WEBER: 00:37 Your journey with brain injury developed, really, from a personal story. Would you mind sharing with us a bit about how you got involved in the brain injury community?

JOE CONCATO: 00:47 My wife, Jane, had an accidental fall at home on March 15th, 2004. At that point, after the required calls to 911 and everything else, she was admitted to the Hackensack University Trauma Center where she spent approximately four weeks going through acute care and the beginning portions of rehabilitation. From there she was transferred to Kessler Institute for Rehabilitation in East Orange where she spent another four weeks of inpatient rehabilitation, and then approximately 18 months of outpatient rehabilitation.

ERICA WEBER: 01:25 So it's been now-- is that 16 years? Am I doing my math right?

JOE CONCATO: 01:29 Yes.

ERICA WEBER: 01:29 That's quite a long time and a long journey. How have you been doing, Jane?

JANE CONCATO: 01:33 I've been doing well. As I say, I've come back very well. I have some deficits. My speech isn't that great. I have anomia; I forget words. I had speech therapy for a while. I have anxiety, post-traumatic stress, and a little more depression than I probably had before my brain injury, which really wasn't a lot, but now it's definitely more.

ERICA WEBER: 02:03 Yeah. So it sounds like you've had a number of challenges since that fall, but it sounds like you were able to get right into getting some good quality care. And you said you've come back quite a ways since your first injury.

JANE CONCATO: 02:18 Yes. Yeah.

ERICA WEBER: 02:20 Wow. And I bet that wasn't the easiest road.

JANE CONCATO: 02:23 No. There's been a lot of good and a lot of bad. The bad things, I'm not even going to say, but I guess they're common after brain injury. You lose friends. You know who your true friends are. I've had some falls. I have a balance issue. I've had seizures so now I'm on a seizure medication. But we've had, really, some of the greatest times of our lives now.

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- ERICA WEBER: 02:54 So it sounds like it's been really helpful that you could see that even though there's been-- in those challenges and struggles that have come since your brain injury, that you can also see positive changes that have been able to happen in your life.
- JANE CONCATO: 03:09 Definitely.
- ERICA WEBER: 03:11 What made you take this personal experience that could be considered negative by many and turn it into something that made you want to give back to the community? How'd you start getting involved in volunteering?
- JOE CONCATO: 03:28 We both come from a family of volunteers in the emergency services in our local towns, and we still volunteer to this day. As Jane was an inpatient at Kessler Rehabilitation, I was informed of support groups that existed at the time. And when Jane was in inpatient I never really went, because that was my opportunity to spend time with her in the evening. And I don't remember the specific timeframe-- at some point after we were home, but still in touch with the folks at Kessler for case management and everything else, we decided to start attending the Essex County support group. And I think that came from our volunteer efforts. And we started to understand more about brain injury, realize that there were other people going through similar things, sharing some of our stories, and learning from others.
- ERICA WEBER: 04:22 So you benefited from the support groups that, down the road, you ended up leading.
- JOE CONCATO: 04:28 Absolutely.
- ERICA WEBER: 04:30 What did you find most helpful about the support group?
- JOE CONCATO: 04:33 Knowing that other people were going through the same things; knowing that what we were experiencing was not out of the ordinary for someone with a brain injury; learning about organizations and resources that we're out there to assist, such as the Brain Injury Alliance of New Jersey.
- JANE CONCATO: 04:50 I specifically wanted to go back to Kessler at East Orange. I wanted to see how the survivors that were in my cognitive therapy group-- I wanted to see if they'd be there - and many of them were in the support group - and talk to them again and see how they were doing.
- ERICA WEBER: 05:06 So it was a social connection for you. And I'm sure, at that time, who you were meeting on the rehabilitation unit, that you probably spent a lot of time together undergoing the same types of rehab and going through similar therapies and being able to maintain those connections that were forged in the context of a tragedy.
- JANE CONCATO: 05:28 Definitely. I always considered my cognitive remediation group-- there were usually about 12 of us in a room in the morning, and we'd get teased out for specific therapies. I always considered that group as my first support group, because I did learn things from other people, and everybody was kind and it was good. I didn't want to go, but I did, and glad I went.
- ERICA WEBER: 05:57 That's not uncommon. Because initially it's scary to jump in there and be able to share your story and be open to hearing other people's stories, especially if you know it might be something that's sad or bring out those [tough?] emotions in yourself. But it

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sounds like you were able to get up the courage to go and open yourselves up to that experience and find out that it could be very helpful.

JANE CONCATO: 06:21 Yeah. I would recommend it to anybody, and I would do it again if I had to.

ERICA WEBER: 06:27 So you were a member of the support group through BIANJ for a number of years, and then more recently ended up leading it. Is that right?

JOE CONCATO: 06:37 Yes. After we started attending the Essex group, we learned of a separate group in Bergen, which was really around the corner from where we live. So we thought with all the benefits we were receiving from Essex, we started attending the Bergen group also, and got the same benefits out of it with a different set of people and little different circumstances, but still the same overall issues, understandings, and everything else.

ERICA WEBER: 07:02 And isn't it amazing that just being able to hear-- to get a different group of individuals, you hear similar types of stories, but you can get different perspectives or different ideas of things to try in your own home.

JOE CONCATO: 07:18 Absolutely. There were always new ideas coming from everyone in the group. After we started attending the Bergen group for approximately a year-- there was a neuropsychologist who was facilitating it, and she realized that she couldn't facilitate it again because she was starting a practice and a family. So she approached us to see if we'd be willing to take over the facilitation of the group on a temporary basis. I immediately agreed to; Jane questioned at the time. But the temporary basis started in January of 2007.

ERICA WEBER: 07:59 Quite a long time ago at this point.

JOE CONCATO: 08:01 It certainly was. Depends on your definition of temporary.

ERICA WEBER: 08:04 Sounds more like you did too good of a job for it to stay temporary.

JANE CONCATO: 08:08 We love doing it.

JOE CONCATO: 08:09 We embraced it. It's even more than an extended family. It's just family.

ERICA WEBER: 08:15 And what is the group doing now during the pandemic? I imagine you can't meet in-person anymore.

JOE CONCATO: 08:21 That's correct. We're not meeting in-person anymore. We have started online virtual groups.

ERICA WEBER: 08:28 Oh, fantastic.

JOE CONCATO: 08:29 We missed the March meeting, just because of timing and everything else that was going on, but we had a virtual group on the normal night of our April meeting. Had approximately 30 people on the video conference, and it went very well. Before everyone dispersed we raised the option of having another one in two weeks, as opposed to once a month, and everyone thought that was a great idea. So at this point, we're having two online virtual meetings a month, as opposed to one, just for everyone to stay in touch, to share stories, to see one another with the video conference, and everything else.

Volunteering Has Given Us Both a Purpose - 2020 Brain Injury Alliance of New Jersey (BIANJ) honoree Jane and Joe Concato

- ERICA WEBER: 09:10 So you found that it worked so well that it was beneficial to not only continue the meetings but to up their frequency. And I bet it was nice to be able to see people that you find comfort in and who can understand what's going on with you right now.
- JOE CONCATO: 09:30 Yes. Certainly, from our perspective, and that's what we heard from everyone else who participated in the virtual session.
- ERICA WEBER: 09:36 Well that's fantastic. I think it's definitely been one of the stories of this pandemic, that people are realizing how to get in touch with people who either might be living further away or when you have some challenges in being able to get out of the house. And that does often happen after brain injury, that transportation can be a problem due to being unable to drive or needing work around different schedules. So it sounds like this has actually been a change that could make it more accessible in the future for members of the support group.
- JOE CONCATO: 10:13 Absolutely. We haven't broached the subject yet, but I can see the possibility of, moving forward, having a regular face-to-face meeting as we normally do, but maybe on some other night during the month having an online meeting just for people who may not have been able to make the meeting for any number of reasons or people who don't normally come out because they have issues driving or any other scenario.
- ERICA WEBER: 10:41 That sounds like a great idea. The support group is lucky to have you both at the helm, and it sounds like you bring a unique perspective by being able to speak from experience, but then also being able to be-- to be able to hear other people's experience and facilitate that at a group level. So I think it's definitely a skillset that is clearly prized by the community.
- JANE CONCATO: 11:10 We're happy to do it.
- ERICA WEBER: 11:12 I know you both as our frequent-flyers of research participants, so we're always grateful to have you in our research studies. And you also come in for other sorts of roles as well. Could you tell me a bit about those other roles that you have with us?
- JANE CONCATO: 11:27 I am part of the IRB, the institutional review board. We meet once a month at the foundation. We read studies to make sure they are appropriate.
- ERICA WEBER: 11:39 Right. So that's our ethics review board to make sure that all the research studies are being conducted and everything's above board. And we always have someone from the community on each of those. And it's great to have someone fill that role so we understand that things are being conducted, in terms of our research, from a perspective that is appropriate, from the consumer's standpoint.
- JANE CONCATO: 12:07 At first, I didn't think I could do it. I had to take a test. I had to read a lot of online questions and answers.
- ERICA WEBER: 12:15 Yeah. They probably had you go through-- right, going through a lot of the training that we get as scientists, as well, about all of the important research principles--
- JANE CONCATO: 12:26 The principles. Yes.
- ERICA WEBER: 12:26 --[inaudible] [the people?] that they can maintain their independence.

Volunteering Has Given Us Both a Purpose - 2020 Brain Injury Alliance of New Jersey (BIANJ) honoree Jane and Joe Concato

- JANE CONCATO: 12:31 Right. And my reading comprehension-- it's gotten a lot better. It was very difficult. And of course I called up the person who had-- not nominated me, or asked me to be part of the IRB group, and I said, "I can't do it. I can't do it." And she was like, "Calm down. Calm down. You could do it." And I did it. I passed all the parts of the test. And it's one of the best things I've ever done. I've learned a lot about my own brain injury, and it's been good.
- ERICA WEBER: 13:06 And I know we-- yeah. I know we benefit from having that comfort that we know that our research protocols are being reviewed before going out to research participants by people who may be part of our participant population. So we appreciate that role, and it's good to have those checks and balances in play. You also both serve on our Traumatic Brain Injury Advisory Board. Is that right?
- JOE CONCATO: 13:33 That is correct. Yes. We're happy to participate in those meetings and share our opinions on items related to research, conferences, newsletters, and all other information that's out there, to assist people impacted by brain injury.
- ERICA WEBER: 13:50 Yeah. So I think, all told, you've had quite a huge volunteer presence at Kessler foundation, particularly in shaping how we do our brain injury research, from vetting the studies to vetting the overall way that we conduct research and how we outreach to our community, and then also to being part of our research studies. When we heard that you were being awarded the Volunteer Service Champions Award through BIANJ we were not surprised in the least. It couldn't go to two more deserving people. And also, I must note for the posterity of the podcast that beyond your volunteerism, of course, Jane, you are famous for your lemon bread that you never fail to bring in to us at Kessler Foundation whenever you do stop by. So it really is like you're getting double volunteer service every time you do come by for a meeting, so we absolutely appreciate that as well.
- JANE CONCATO: 14:48 You're very welcome. If you ever want a lemon cake just let me know. I just wanted to mention that I'm a dental hygienist, and a few months after my brain injury I realized, at that point, I could not go back to work. I had broken my wrist. So one of my case managers said, "Well, what are you going to do when you're discharged from the CRP program?" And I had talked to the woman that was doing occupational therapy on my wrist every morning, and she said, "Why don't you make Lucy," my Shetland Sheepdog, "into a therapy dog?" So that was my big push of what to do after I left CRP. Because you literally leave CRP, and you're just-- that has become your new group. I remember the day I found out that my insurance had stopped, and I remember driving away saying, "Now what? What do I do now?"
- ERICA WEBER: 15:52 That would be a big loss after you've created those bonds and found that support.
- JANE CONCATO: 15:56 Yeah. Not knowing that I would eventually go back for other things, but. So probably about a year-and-a-half later-- because you know about cognitive fatigue; it's just so overwhelming. But Lucy became a bright and beautiful therapy dog. Kessler in East Orange did have therapy dogs come at night. I don't remember them, but I wanted Lucy to come during the day when the patients were having therapy, because I remember how difficult it was, and this way I could just walk around with Lucy.

Volunteering Has Given Us Both a Purpose - 2020 Brain Injury Alliance of New Jersey (BIANJ) honoree Jane and Joe Concato

- ERICA WEBER: 16:38 You need a bright spot. As a dog lover myself, I can understand that that would be really a bright spot for someone's day and give them some motivation to keep going and just a little bit of positive energy. So even your dogs are volunteers is what you're saying.
- JANE CONCATO: 16:56 Oh, yeah. Yeah. I always had a little outfit on her-- something around her neck for the holidays or Christmas or whatever. And the therapists themselves would say, "Can I touch her?" I mean, obviously, she wasn't a companion dog, "Can I touch her?" And I said, "Sure. She's here for everybody." And after East Orange closed, she went to West Orange-- we both went to West Orange, and there was a picture-- they did hang a picture of her up when you come into West Orange. And I was proud that Lucy was West Orange's first therapy dog.
- ERICA WEBER: 17:44 She's probably touched many patients' lives the way that you probably would have benefited from that as well.
- JANE CONCATO: 17:52 Yeah. Definitely.
- ERICA WEBER: 17:55 And it's nice to be able to share that gift with other people.
- JANE CONCATO: 18:02 I would take her around to patients and-- I would see them upset, and they weren't speaking, and I would say, "Oh, I have a brain injury. I was here. This is a great place to be, and this is Lucy." And there was one day where the therapist came over and said to the patient, "What is the dog's name?" And the patient said, "Lucy." And the therapist looked at me and said, "That's the first word this patient has said since they were admitted."
- ERICA WEBER: 18:41 Oh my goodness.
- JANE CONCATO: 18:41 So I started crying, but that's normal.
- ERICA WEBER: 18:44 Oh of course. Yeah. You're going to have me crying over here too. But that shows how those sorts of little things can really change someone's life-- change their rehabilitation and get them-- if that was the breakthrough that was needed, then she was able to give that to them, and you through her.
- JANE CONCATO: 19:06 Yeah. Yeah. It gave us both a purpose, so that was a good time.
- ERICA WEBER: 19:12 I just wanted to know, what sort of advice do you have for people with brain injury, particularly during this challenging time? How have you been getting through and coping with the stress of the pandemic, or what are some words of wisdom that you might have for the community in general?
- JANE CONCATO: 19:29 I would say for the survivors, and even the caregivers, "Don't be hard on yourself. Be gentle to yourself." I am on Facebook, and also YouTube, and I've been reading a lot of things that people are doing. They're learning how to speak French during this time. They're becoming gourmet chefs. They're tightening their abs. To me, this is like, "Oh no. I can't do it. It's too much for me." This should be a time to just rest and take care of ourselves; listen to our medical physicians; don't watch the news that much; learn your social distancing; call a friend on the phone; don't text them, just call them and talk to them; think about good memories.

Volunteering Has Given Us Both a Purpose - 2020 Brain Injury Alliance of New Jersey (BIANJ) honoree Jane and Joe Concato

- ERICA WEBER: 20:22 So really appreciate what you have. It sounds like you've been spending a lot of time kind of getting back to basics and going through what's important.
- JANE CONCATO: 20:30 Exactly.
- ERICA WEBER: 20:31 I wanted to thank you both for sharing your experience with us. And again, congratulations on the award, and we're incredibly proud of both of you for going through this experience and giving back to the community with such courage and being a model for those survivors and their caregivers. So thank you for that, and thank you for talking with us today.
- JOE CONCATO: 20:58 Thank you, also.
- JANE CONCATO: 20:59 And you're very welcome, Erica. [music]
- ANNOUNCER: 21:03 Be sure and check out Jane and Joe's Volunteer Service Champions and acceptance videos, TBI consumer resources, and research study opportunities by clicking on the links in the program notes of this podcast. Tuned into our podcast series lately? Join our listeners in 90 countries who enjoy learning about the work of Kessler Foundation. Follow us on Facebook, Twitter, and Instagram. Listen to us on Apple Podcasts, Spotify, SoundCloud, or wherever you get your podcasts. This podcast was recorded on Wednesday, April 29th, 2020, remotely, and was edited and produced by Joan Banks-Smith, creative producer for Kessler Foundation.