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Proem 00:52

You know the old story of the researcher looking for their lost keys under the streetlight when they lost them in the dark alley. ‘Why aren’t you bringing the light into the alley?’ ‘Because the light’s already here in the street.’ OK. Not necessarily a fair story. The researcher might not know that they’ve lost their keys.

People with lived experience certainly know that keys are lost, and sometimes they can ask the questions to help find them. They ask questions to use the answers to make decisions with their clinician partners about their health and treatment. I often shake my head in wonder when I listen to scientists and funders who stubbornly lack awareness of the value of patient-caregiver partnership in all phases of research and clinical trials.

Introducing Lynne Becker 02:17

Health Hats: Lynne Becker, a clinical trials research expert, knows the value inside out as a research scientist and a mother of a daughter with Traumatic Brain Injury (TBI). I asked Lynne to introduce herself.

Lynne Becker: Hi, I am Lynne Becker, the CEO, and founder of [Power of Patients](http://www.powerofpatients.com). I come from the clinical trial world over the last 25 years as a biostatistician and epidemiologist. I managed and designed all



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sorts of clinical trials. I decided to launch this company specifically to help people with brain injuries and reshape the course of clinical trials in this space.

Understanding Traumatic Brain Injuries 02:44

Health Hats: OK. So, reshape because reshape implies that you were less than delighted with how it was before, and you wanted it to take a different direction?

Lynne Becker: Yes, that's a smart way to say it. My goal is to characterize the TBI population because it is very uncharacterized, and because of that, it's misunderstood. A simple example is that no two brain injuries mirror one another and not even in the same person. Typically, what happens in clinical trials is you first take the time to slice and dice and understand the population and what is happening to them before you start designing trials. That did not seem to be the case when I pulled all sorts of research papers in clinical trials of brain injuries. We're creating clinical trials based upon devices coming up or repurposing drugs currently being used in one area, and thought may have some indication in the brain injury space. But it's a very heterogenous population. Therefore, we must start at the basics and understand the symptoms, what the makeup is, something other than your very traditional demographics of age and gender, and things like that. Then ultimately reshape from the patient's perspective, how the clinical trials will be designed to address their symptoms and triggers, and things like that.

Health Hats: OK. To me, things that appear to be individually unique are often more the same than some people think. Or maybe it's differently individually. What I'm trying to say is, 'do you find that even though when you know one TBI traumatic brain injury person, you know one brain injury person? But you can categorize somehow based on function or cognition or whatever. What are those kinds of things that you have found that you can group people?'

Lynne Becker: Some high-level groupings currently do exist, to what you're saying. You have cognitive impairments; you have physical impairments; you have balance issues, sight issues, and emotional issues. So, those high-level things exist currently. Let's talk about two specific kinds of injuries - a closed head injury versus an open head injury. Someone that doesn't have an open gaping wound and somebody who does. You can often visually see that open gaping wound, even after their hair grows over and things like that. There are clear differences between that person's emotional problems versus the person with a closed head injury. The closed head injury people may or may not - this is part of the problem - get better or it may worsen with certain other triggers. And these are like the hidden symptomology or the hidden triggers that suddenly, it's like an onion, a new thing just blew up. And what was it that caused it to blow up? People with acute conditions typically have a very open head wound or even in a neck injury that's very clear to be seen. You're able to give them good acute care in the very beginning, but once they get past that acute stage, they seem to be mirroring what a mild case or somebody with a closed head injury is now experiencing, too. Those are some of the challenges. Even though we say, 'OK, you have emotional issues' or 'OK, you have cognitive issues.' You still cannot drill down to the real essence without understanding triggers that cause them to get worse or what gets



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them better. That's what we also want to know. Can't get them better. Some people don't know; myself included, that my daughter had a vision impairment. So, it wasn't until I did a lot of digging and research that I could figure out that this doesn't make sense; she should go and get this checked. At least take it off your list and make sure that you've addressed it. So, your brain is amazing because it's going to figure out a way around it. If you think of a sprained ankle, you're going to limp for a little while. If you have a brain injury, you're going to be sleeping for maybe a long while. You just don't know. Your brain is going to shut your body down. But with a sprained ankle, your body is going to figure out how I can walk without rehabbing it? You can use that simple analogy, even with your brain. If you don't get the right rehab therapy, your brain will figure out a way to compensate or work around this deficit.

What change are you trying to make? 08:27

Health Hats: OK. So, what are you, what change are you trying to affect with Power of Patients?

Lynne Becker: I am trying to change how clinical trials are designed. Typically, if you have a clinical trial designed, they stay at this very high-level grouping, just like we discussed. But they don't dig down into the true etiologies of these symptoms. And when does it flare-up in a certain person? You, if you have a TBI, you might walk outside, and if a bus goes flying by or a siren, it might send you into a panic attack. Somebody else can handle that. But we just don't know. Or maybe they go to a mall, and they flip out like they have to go home immediately. That's the minuscule issues that must be well understood and they're not. Right now, research, clinical trials, and our knowledge remains at this high level instead of drilling down to the nuances amongst individuals. Suppose we're able to find enough people in these nuanced categories. In that case, we'll have enough people for clinical trials so that we can design them specific to the idiosyncrasies they present with.

Answers to what questions? 09:49

Health Hats: So, it sounds to me that there are two parts to this. What are the questions that research is answering? And how is the trial designed so that it can answer the questions with some specificity to that they're useful answers?

Lynne Becker: Yeah, I think that's a good way of looking at it, for sure. Definitely on the second half simply because what are the questions that they need to answer specific?

Health Hats: OK. I find in my experience that they are usually researchers or clinicians. It's not often the person with whatever or the people who are part of their caring network. Those kinds of questions can sometimes be wildly disparate.

Lynne Becker: Yes. I think you just said it perfectly. What they think is happening - they being the clinicians and the researchers, and I'm speaking from experience because I come as a researcher and a clinician, what I thought was or wasn't happening to my daughter was completely off base. She looked so normal. I could not figure out for the life of me why either behaviors were happening, or she was just not able to function. What was going on? So that's the incorrect supposition. We think we know until you live the life of the actual person or the caregiver. That's what you need to hear.



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Health Hats: I looked at your TBI dashboard. Did you design that because even if you are asking relevant questions to patients and caregivers, the data that's available in electronic health records and claims data, which is often the source of much information that's being used in clinical trials, is insufficient. And that patient and caregiver recorded data may be more relevant. Tell us a little bit about your dashboard.

Electronic records, ICD codes, and Zebroids 12:39

Lynne Becker: First, your observation about the EMR, the electronic medical records system, is correct. It comes from this 'what they think is going on' perspective. I had to give a little backstory to your listeners. The EMR record systems are populated because of ICD codes that exist after years and years of rigorous research in a specific indication, and the codes are there one of the problems, and there are several, but one of the issues with the ICD code system to be able to identify patients for clinical trials in TBIs, is that there aren't enough ICD codes to put them in the bucket, right? So, they end up going over into a completely different category because that's the only category they can find to match their ailment when the real issue is TBI. So maybe you have cognitive problems, but the cognitive problem is a result of the TBI. So, ICD codes are building, but they're not anywhere near where they should be.

*We should talk about ICD codes for a minute. [International Statistical Classification of Diseases and Related Health Problems \(ICD\)](#), a [medical classification](#) list by the [World Health Organization \(WHO\)](#). It contains codes for diseases, signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases. ICD codes are the child of billing and clinical information, sort of a zebroid. Every clinical encounter needs an ICD code – now in version 10 – to bill. As the ICD system evolved over the years, more and more codes have been added. There are over 70,000 **ICD-10 procedure codes** and over 69,000 **ICD-10 diagnosis codes**, compared to about 3,800 procedure **codes** and roughly 14,000 diagnosis **codes** found in the previous **ICD-9**. There are no ICD codes for hungry because you can't afford food, or down and out, or just plain scared. ICD codes represent a point in time, a snapshot, not a life. Assigning codes is a billion-dollar industry. Let's jump back in.*

One of the things that also happens is you might go to your doctor every two months or every three months, right? Once a year, that is a snapshot in time, right? That is not the real-time course of events of what that person is going through. So, my dashboard tracks real-time data for the person so that they can actually see, 'OK, I had a spike in my anxiety.' We ask them specific questions to help them figure out what caused the spike, think of [MadLibs](#), so they can fill it all out, and then they get this report, and they can bring the report is a timeline, a trend analysis if you will, to their doctor. So, this is what's happening.

Birthing precision, personal care 16:29

Health Hats: Whatever chronic thing - chronic pain, multiple sclerosis, like I have, or TBI, or whatever - this journaling and finding patterns and then the N of one experimenting is such a challenge.



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Lynne Becker: But it's true personalized care. And it empowers the patient, and that's huge is the patient no longer has recall bias. They can do this on the fly. And they can say, no, doctor, this is what happened.

Health Hats: So powerful. But the challenge is that this real-time journaling, whatever you want to call it, and having it in a searchable and manageable and analyzable - if that's a word - form is helpful. But I find the challenge with that is that the analysis of it is also a team process. For the most part, clinicians, depending on their specialty, will see certain patterns. The caregiver may see others. Analysis requires a combination of all those perspectives. You've been talking about asking the important questions, designing, selecting data, redesigning research, and analysis. This must be something that I'm sure you've built over the years. This is not something that you birthed whole.

Lynne Becker: I worked fast.

Health Hats: I'm sure. Having your experience makes that possible. But I imagine that - correct me if I'm wrong cause I really don't know you and I'm making all sorts of suppositions, feel free to blow up my suppositions - but that you started out because somebody or some people in your family had this challenge and you wanted things to be different. And you had the knowledge and experience and energy to move forward. But moving forward, I don't know, but all of those things and a buck and a quarter will buy a Pepsi as far as I'm concerned. It takes coalitions and infrastructure, and there's just a whole sort of like a business part of moving this forward. So, can you tell us a little bit about that evolution?

Murphy's law merry-go-round 19:45

Lynne Becker: Sure, of course. Listen, if it were as easy as you just described it, goodness gracious, that would be a miracle in and of itself. It has been birthed over, let's say, five years when my daughter was injured in 2015 with a severe traumatic brain injury. A few days after her injury - her optic nerve was torn when she got hit and things like that - Murphy's law of everything that was going to go wrong in the healthcare environment and her school, it all went wrong. She was away at school. A few days after her injury, she stroked on top of it. What's even more insulting is that the school and the hospital were part of the [CDC Heads Up](#) program. It gets crazier. The electronic medical record system went down. They took her to urgent care, not to the children's hospital. It was one thing after another. So, that's a whole other two or three podcasts. But because I believe in clinical trial research - that's what I do - I believe in what we do, but I also believe in making sure people are treated fairly and wholly as well. We were in Charleston, South Carolina, where we used to live, and I was taking her to what I thought was the best of the best doctors that I knew down there. They all kept saying just a concussion. She just needs a rest. I would look at her eye and I would point it out to them, and I'd say, but her eye is messed up. You can just see it. It's right there. You don't have to do some special exam. It's not working and just rests. We think her vision will come back. I'm like, you think so? I'm going to put a little salt on my wound here. Eleven inches of historic rainfall hit our home when she was having this very acute case happen. Then subsequently, we had three hurricanes hit our house as well. So, I'm dealing with a child who can't be



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moved. She couldn't see. She had panic attacks and never woke up. Like this child was Rip van Winkle. I kept listening to them, and I drank the Kool-Aid as I tell everybody. But it was getting frustrating because I kept hearing that same broken record. She just needs to sleep. OK, how long, it's been two months now, and she's passing out? She's sitting up in bed, and she's passing out. How do you explain that? And they're like, she has to start exercising. So, we take her to a teeny, little exercise class, and in less than two minutes, she's on the floor because she passed out. What the heck is going on here? So now I start asking these questions, and I start asking them vigorously. I start pulling research, and I'm finding nothing, nothing of any current relevance, maybe in the seventies. OK, maybe I'm not looking correctly. I kept saying, perhaps it's me? Fast-forward and she's starting to stay awake a little bit longer and things like that. But nothing from where she was. She had to be removed from school, and I homeschooled her, and I'm thinking, how do I teach somebody like this? Her academic status went from 98 percentile to 37. This is mentally challenged. How do I teach her? She couldn't stay awake, and she would be having little panic attacks, which became really exasperated—even trying to memorize the pledge of allegiance, something simple like that, that we all know. So, then she can't walk, and she couldn't remember how to crawl. She couldn't remember how to run. We are now a year and a half into it. I'm now going to another neurologist who might help me. It wasn't until one doctor said to me, you're just here because of the movie. Now, at this point, I'm bringing binders. The movie he's referencing is [Concussion](#). I said, 'I'm here because my daughter is - I don't know what she is, and I need help.' I couldn't even explain it. She couldn't explain it. He didn't even look at her charts, and I thought, how dare you? I'm quickly losing my faith in the profession I work in.

[Eureka, a light at the end of the tunnel. 24:26](#)

So, I write a letter. I was given two names to a couple of doctors, one in New York and one in Philadelphia. And I write a letter to them because they had presented at a concussion conference. I didn't hear back for a little while. In the meantime, I had started hiring radiologists thinking something's missed here. What is going on? Can we maybe reread their films, and five, six radiologists is what it took. When I finally got to the sixth one, the doctor said, 'I don't know, who's telling you this as normal, but your daughter has severe spots all over her brain.' Your heart stops because the whole time you're being told she's fine, it's just a concussion. Take a chill pill, mom. In your gut, there's something wrong. And at this point, I'm carrying binders because I started tracking her so I could explain stuff. They were disinterested to be honest with you. Then the two doctors contacted me that I wrote emails to. The first in New York put it out there, just like, boom. What you're telling me is not a concussion is a traumatic brain injury. Then oh my God, number two, what do you mean? He then goes on to explain how she really can be managed better. This is not the treatment that she should be getting. I said, 'can I come to see you?' I need you to see a neurologist first. This was a neuroendocrinologist. And then I got up to CHOP (Children's Hospital of Philadelphia) to the other neurologists that I wrote the email to. She immediately said, come up, we can help. And it was the first time witnessing a two-and-a-half-hour intake. It was the first time that I felt, as did my daughter, that, Oh my God, there's hope. Now you can get the right therapies. So that's a year and a half in before anything happened. Then it was a matter of finding all the kinds of doctors at our home to take care of her. This was the basis of how I started



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building the dashboard because I had to keep communicating what was going on to all these therapists and doctors, and rehab specialists.

Health Hats: And you got to get those binders down to a page?

Lynne Becker: Exactly. Totally. But they all loved it. I will say this. They all wanted these copies, so that was good.

Now a word about our sponsor, ABRIDGE.

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From mom in trouble to the business of advocacy 27:47

Health Hats: OK. I guess what I'm interested in this minute it that you made an organization, an advocacy organization. You went from being the mom of somebody who was struggling to deal with whatever she was dealing with to thinking about the larger community of people with TBI. You got this cool logo like that's a business thing to do. So how have you built that, that outwardly facing business of power of patients?

Lynne Becker: Yeah, thank you. That's a great question. I give the impression that I am just an advocacy group on my website, to empower and educate people and their caregivers, but it's much more.

Health Hats: Yes. You don't fool me.

Lynne Becker: Initially, when I did that, I didn't have my dashboard live. I also had not been able yet to figure out how I now take this very valuable dashboard and monetize it. Because, and how do I do it so that I can keep it alive and support myself? I did think I was the only one going through this craziness. When we kept going from doctor to doctor until I realized there are tens of millions of people, I'm not an anomaly. And then that was the,

Health Hats: Isn't that a great moment?

Lynne Becker: Yeah. Yeah. That was the other tipping point for me because I'm like, this is crap. There's no research going on, and it's your brain. It's what runs your whole body? Nobody was in the TBI advocacy space, and that's how I ended up getting my page one SEO (Search Engine Optimization) rankings. I did all the research behind the scenes. That's how I can be found. Otherwise, nobody's going to know who I am. Once I did that, I started creating all the blogs. So, working off my clinical trial research experience where I would do patient recruitment and education, I started taking that. I started putting it out there socially through Facebook blogs by reaching out to different brain injury groups and talking to people who would listen. We started at zero. I have self-funded the whole thing at this point,



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but we started at zero in July and then we started with Facebook and Twitter, and Instagram. Again, I was no digital media expert, but now with our followers, we do everything privately on our dashboard, but we let people like and follow us. We have a little over a thousand across the platforms. And this is only since like July 5th, 2020, when we started. Yes. I just started the company last year.

Health Hats: Oh my God. You could have fooled me. Wow. It looks more mature than that. I know that's not the right way to say.

Partnering with the Veterans Administration 30:59

Lynne Becker: Thank you, I appreciate that. I took the first six, seven, eight months building it, testing it, building the dashboard. I've done this for my career. I knew how to do that. I worked off my experience as a caregiver, and then worked off my experience when I managed the TBI portal for the US government and the soldiers. That was how I started to reshape what I was doing.

Health Hats: Wait, back up, what's with the soldiers? I missed that.

Lynne Becker: When my daughter was injured, I got fired from my university job because I had to be her full-time caregiver. They would not allow me to work remotely. I had to eventually figure out how to support us and find a job. I ended up going to work for the Department of Defense in a subcontract position. I was one of the team that built these massive data warehouses for the Defense Health Agency. I ultimately was recruited to redesign the VA system. I was then brought over to manage the traumatic brain injury portal for the special OPS teams for the government.

Health Hats: Wow. What an opportunity.

Lynne Becker: Yes. I saw the mappings of the soldiers, and I thought this is my daughter. Who is mapping this? I need to find this person. That was my motivation. It was very selfish. I wanted this doctor to treat my daughter, and fortunately, I got there, and I started working with the whole project, and I even found therapies for my daughter that work well, and we're not being told to me to use for her—one of it being [QEEG](#), which is biofeedback.

Health Hats: Now wait, say that again because I didn't get it.

Lynne Becker: QEEG is a biofeedback therapy.

Recognizing success – pause and trust 33:09

Health Hats: I'm going to ask you a different question. Now, when you're doing this Power of Patients thing, how do you recognize success? What's going to happen that you feel like you hit a home run?

Lynne Becker: Man. That's a great question. Can I answer it in two parts? My mission is to empower patients with TBI and their caregivers. Success is when I get an email like today from a patient who attended our webinar, loved our demonstration of the dashboard. She's from St. Jude's Hospital and she herself is a survivor. She can now set up an appointment with the vision therapy doctor because she



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knew she had vision problems. But her neurologist kept saying, no, you're fine. She took the virtual webinars. So that's a success.

Health Hats: OK. This is the success of one person who took a one-step on a solid path. OK. Go ahead.

Lynne Becker: Other successes are around patient empowerment. I had another patient say I stopped running to the ER because I could figure out a pattern of my migraines.

Health Hats: Precious. I so get it. Absolutely.

Lynne Becker: Yes. And then now a mom caregiver, a veteran herself, her youngest daughter in a coma for a year introduced me to the [Elizabeth Dole Foundation](#) because caregivers are what they call *hidden heroes*. And they are creating an initiative where caregivers and providers in the VA talk to each other. That's the success. They have seen my dashboard

Health Hats: That's a monster success, a system success, right?

Lynne Becker: So, that's the two parts. My successes are all for the patients, motivating me to keep pushing it with that army behind me. I want us to become this force as we move up the health care chain.

Health Hats: OK. So, people are dealing with different flavor challenges, but it sounds somewhat similar. Something happened to them; something happened to a family member; something happened to a loved one. They made it through the acute phase with great difficulty, and now they have the energy to give back. That sounds like what you're doing. What do you think if you were going to give people those people two lessons that you've learned that you wish you had known six months ago? What might some of those be?

Lynne Becker: The first lesson: as a caregiver, lots of times you want to quit. Don't quit, pause. Pause and regroup for yourself because honestly, you are the lifeline for that person who needs you, but you yourself must take care of yourself.

Health Hats: Self-care, man, isn't that monster. I'm with you a hundred percent. I think now in this COVID world with all these healthcare workers, whether they're licensed or not licensed professional or not professional, they have to take care of themselves because we need them. Yes.

Lynne Becker: Pause.

Health Hats: I like that. Pause. That's a good one. Pause.

Lynne Becker: You can't leave. You can't quit, but you do need a break. That's especially important. The second lesson is to trust yourself. I knew they were so siloed in their approach and they weren't looking at the big picture. Again, to the beginning of our conversation - what's the difference in an EMR? The EMR is three months, six months, nine months, right? This is a timeline. Yes. Trust yourself. Something isn't right. Pause and trust.



Health Hats: I like that. I like that a lot. What should I have asked you that I haven't?

Lynne Becker: What should you have asked me? I don't know. You did a pretty darn good job. Go to the website, send me a message. We have some conversations going on with the [Michael J. Fox Foundation](#). They're looking to go into the strong correlation between traumatic brain injury and people with TBI developing Parkinson's, same with Alzheimer's.

Interestingly, we have a ton of stroke people who are now finding our website and starting to use it. Don't be afraid to ask me to build out a platform-specific to an indication because that's what I do easily. I want it to be robust enough to use for multiple sclerosis. To apply to everything. I don't have anything else to share. Just go to the website, spread the word.

Health Hats: Thanks. Yeah. All right. This is great. Oh, good. Thank you so much. Listen, I appreciate it so much.

Reflection 39:17

Research often feels like taking snapshots in a rear-view mirror when people's lives are more like movies on a windshield - continually move forward. The methodologies of research prefer the single moment, back-looking approach. When I participated in Merit Review for PCORI (Patient-Centered Outcomes Research Institute), I felt frustrated that rehabilitation studies seldom gained approval. Merit Review is the review and scoring of comparative effectiveness research funding requests. Since individuals get better (rehab) differently, the comparison of approach A versus approach B can be challenging to design. Rehab is itself a persistent experiment of learning about and reinforcing new abilities. That experimentation includes learning what works and when it doesn't, trying something else. Lynne Becker's dashboard and trigger approach give me hope. I need to explore that dashboard and learn more about it.

Talking with Lynne reminds me that clinicians and researchers sometimes label people as 'patients and caregivers,' forgetting that we come to the interim roles of patient and caregiver as fully formed experts in whatever we're expert at. Expert statisticians, expert carpenters, expert bus drivers, expert homemakers. Imagine if we had screening tools to quickly learn about patient and caregivers' expertise and then used algorithms to designed care plans to maximize that expertise.

Lastly, I hope we, as a nation, can soon shift our focus from the circus of Washington and national politics to the struggles of everyday survival in this frightening, hungry pandemic. We have so much work to do for each other. Be safe and relatively sane. Onward.



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