Guest: Lisa Jacobson, Ph.D., NCSP, ABPP is the Director of Research in the Department of Neuropsychology at the Kennedy Krieger Institute and the co-Director of the Center for Innovation and Leadership in Special Education (CILSE). A licensed psychologist and pediatric neuropsychologist, Dr. Jacobson’s current research is focused on the neurocognitive impacts of cancer treatment that affect children’s return to school after diagnosis or treatment. As co-Director of CILSE, she is also invested in teacher training programs that develop educators’ skills and their familiarity with neurodevelopment, neurodevelopmental disorders, and neuroscience research. Dr. Jacobson holds an appointment as an associate professor in Psychiatry and Behavioral Sciences at The Johns Hopkins University School of Medicine.

Host: Brandon Barrera is a New York City journalist and Public Affairs Assistant at the Dana Foundation. He writes about books for Cerebrum magazine and hosts the Communicating Brain Science podcast. Before coming to Dana, he provided content to Bronx Net and The Bronx Journal. When not enthralled by all things sci-fi, Barrera is fond of cycling, film, and arguing the finer points of tabletop gaming.

[Intro] Lisa Jacobson: They've just had a difficult diagnosis, they're wrestling with cancer treatment and supporting their child through that. They may have other children. They're trying to keep their job. There's lots of other stressors. And then they're trying to figure out, "Well now how do I get my child what they need so they can learn and continue to be successful?"

Brandon Barrera: You just heard the voice of Lisa Jacobson, Director of Research in the Department of Neuropsychology at the Kennedy Krieger Institute and co-director of the institute's Center for Innovation and Leadership in Special Education. Hello everyone, and welcome to another episode of Communicating Brain Science, a podcast for brain science aficionados made possible by the Dana Foundation. I’m your host, Brandon Barrera, and this week we discuss cancer treatment in children.

As a licensed psychologist and pediatric neuropsychologist, Dr. Jacobson expertly walks us through some of the numerous challenges, neurocognitive changes and otherwise, endured by childhood cancer survivors and their families. We also discussed the critical roles that...
educators and medical professionals play in survivors' lives long after treatment is complete. So thanks for tuning in, and we hope that you enjoy our discussion. Thanks for joining us, Dr. Jacobson.

Lisa Jacobson: Thank you for having me.

Brandon Barrera: I'd like to start by asking, could you tell us what a neuropsychologist specializes in?

Lisa Jacobson: Absolutely. Neuropsychology is the study of brain behavior relationships, essentially in a nutshell. So that means the way in which your brain functions relates to how we behave. And you might have something like an MRI, imaging of your brain, and it can show you structure, but it doesn't tell you how it functions. So in order to assess how well your brain functions or where your brain might experience dysfunction, that's behavior. So we assess through how you talk, how you walk, how you reason, how fast you can do things, how you pay attention. All of those help us understand the impact of a medical condition or a neurodevelopmental condition like ADHD on function, on a child's function, and then later, of course, on adult function.

Brandon Barrera: Can you tell us then what the focus of your current research is?

Lisa Jacobson: My current research really is focused on the impact of treatment for childhood cancer on children's function, their success in school, and their and their family's quality of life.

Brandon Barrera: Keeping that in mind, what are some of the neurocognitive impacts of cancer treatments, of pediatric cancer treatments on these children survivors?

Lisa Jacobson: I think it's important maybe to start by saying that more children are surviving pediatric cancer than ever before. So the overall survival rate is about 85% overall, and for cancers like acute lymphoblastic leukemia, the most common childhood cancer, that's close to 95% of children survive. So that's very different. In the middle of last century that began to be the case. There were discoveries made such that chemotherapy was now put directly into the brain and spinal cord through a spinal tap. We call it intrathecal therapy. But that has been wonderful for curing disease. However, it causes, in the developing brain, you're putting that into the brain of a one-year-old or a two-year-old or a three-year-old, that causes long term downstream neurocognitive impacts.
Lisa Jacobson: The ones that have been most consistently found in the literature include attention problems. So sort of an ADHD kind of profile in terms of inattention, not necessarily hyperactivity. Difficulty multitasking and regulating cognition and behavior, so executive dysfunction, planning, organizing, managing multiple pieces. Processing speed. So being able to think fast, being able to perform quickly. In some cases being able to do fine motor tasks quickly, like writing, taking notes in class, those kinds of things can be more difficult for children who received the kinds of chemo agents that we now use for many pediatric cancers. There's also neurocognitive impact of surgery. If you have a brain tumor and that tumor is resected or that tumor is radiated, or your whole brain is radiated because of the type of cancer, malignant tumors, then all of your white matter is impacted.

Brandon Barrera: So the type of cancer and the type of treatment could have different impacts.

Lisa Jacobson: Absolutely, yes.

Brandon Barrera: In a recently published research article, you argue for the importance of neuropsychological assessments. Could you tell us what they are and why they're recommended for survivors and their families?

Lisa Jacobson: So neuropsychological evaluation is part of long-term standard care by the Children's Oncology Group, that's in their long-term followup survivorship guidelines. And the process essentially is a comprehensive evaluation of various functional domains. So as I mentioned earlier, learning, thinking, paying attention, talking, motor skills, memory and learning, all of those kinds of domains are assessed because we want to identify the degree of impact that might be related to treatment, or in some cases, children bring their genetic predisposition. So maybe there's a family history of reading disability or a family history of ADHD, so this patient may be more likely to experience as well as direct sequelae or follow long-term effects of their chemotherapy, their radiation, or their surgery. So we try to assess the impact, how that child is functioning, and identify strengths and identify ways that that child might need support. Whether it's referring to therapies, you need behavioral psychology or counseling, you may need occupational or physical therapy, or you need specific supports in school, accommodations or even special education.

Brandon Barrera: Makes all the sense in the world to have one of these or at least opt to go through the process, but it doesn't seem to be the case that they're always employed.
Yes, that is definitely a challenge that we have discovered and continue to work to address. I think some of the reasons for that are because children may look unwell and it may be that the primary focus of the treating oncologist is disease management. And that’s important, right? The disease needs to be treated. They sometimes don't think beyond the immediate physical impacts. You’re feeling nauseous. Let me identify a medication that's going to help solve that. Or you're not keeping food down. These are all really important. So sometimes thinking about the bigger picture, the ongoing quality of life factors that are outside of the immediate medical purview can get lost. They can get overlooked. In some cases, I think providers believe, "We'll worry about that when we're done with treatment," sometimes forgetting that children are actually in school that whole time, or they're actually struggling to do home expectations, do their chores or clean up their room, or those things that are required as part of just life. So I think that's one way it can get missed.

Another way that it gets missed is not every oncology service, department, division has a neuropsychologist on staff. So sometimes making those referrals can be a challenge. You have to know who to send your patient to. You have to have a specialist who knows what they're doing, and that process can be challenging. It's also not inexpensive. So there can be an insurance barrier as well. So if you have insurance that covers it, that's helpful. Not everybody does.

Access to healthcare is always a consideration. So yes, I think my lab is really working now on trying to identify what are the barriers that get in the way for certain patients in terms of being able to access this kind of care? Is it social behavioral determinants of health? Is it provider behavior? Is it just logistics of not having enough time in a visit to fully address all of the things that matter to patients and their families? We don't know yet. It's probably all of those things, but that's something that my lab is actively working on.

What are some of these difficulties facing families of survivors. You deal with these families, you listen to their stories and hardships. What are they sharing with you? What they found most challenging in navigating this new landscape. This is all new to them. They weren’t sure where to go next.
Lisa Jacobson: One of the challenges I think that we’ve really heard from many parents is that that transition from medical care into community supports, generally school supports, is unnecessarily challenging. That it's that return to school transition, or continuing school for children who are already in school. And that process of you hope you're going back to normal, but now you need things that you didn't need before. And in many cases, families have to learn new vocabulary. What is an IEP? What does that even mean? What is special education? What is a learning disability and how do I navigate that process? There's federal laws that guide the special education eligibility and service provision process, and parents are supposed to by law be partners in that process. But when they don't know what it's about, it's hard to be a full partner and not feel intimidated. What has always stuck with me is the parent of one of my patients once told me returning to school was harder than fighting cancer.

Brandon Barrera: Wow. So much to process there. I mean, I think it kind of speaks to also how I, as somebody who's just learning about this, not having to deal with it, how dizzying I was left by everything. There's another language. You just mentioned IEPs. I think there's also the difference between an IEP, which is an individual... And I'm sorry, what is it?


Brandon Barrera: And there's also a distinction between that and a 504 plan. So parents and families have to navigate this new landscape. Who do they turn to?

Lisa Jacobson: That is the question. That's the next question. What we know is that 504 accommodation plans, individualized educational programs, those are all the purview of the school team. Medical providers aren't really trained, they don't really have the background to fully advise or help families navigate that process. So there's a gap. The issue is that the school teams often don't have the medical knowledge that they might need, and when a child comes back to school and looks fairly normal, they're walking and they're talking and they have their hair, it's sometimes hard for schools to fully appreciate the challenges that they've been through. And that's not anyone's fault. It's just how it is. And the combination of missing school for treatment, not feeling well, frequently having to come to the clinic for extra visits and concerns about immunocompromise and possible infection means that they miss more school too.

Lisa Jacobson: So sometimes school teams don't feel like they have a good handle on the children's skills. So who do parents go to? Some hospitals have a school liaison program where there's a designated person or set of
people who follow up and really help with that warm handoff between hospital and school and help parents learn vocabulary and process that they need to know to advocate well for their children. That's not covered by insurance because that is a no man's land. It's not therapy. It's not something insurance typically covers that you can bill for.

Brandon Barrera: Oh my.

Lisa Jacobson: So it has to be funded by hospitals or line items. It has to be funded by philanthropy, grant writing. It's a really challenging spot to fill, but really, really necessary.

Brandon Barrera: So the assistance to navigate a post-diagnosis or post-treatment landscape is not necessarily covered by insurance. So then does it largely fall on the shoulders of parents to take the initiative and obtain information about IEP and 504 plans and implement all these things?

Lisa Jacobson: It really does. That's part of the challenge is that in many cases, the child was typically developing before their diagnosis, so the parent may have had no reason to interact with the special education process or interact with the school in that way before. So they're having to learn... They've just had a difficult diagnosis, they're wrestling with cancer treatment and supporting their child through that. They may have other children. They're trying to keep their job. There's lots of other stressors. And then they're trying to figure out, "Well now how do I get my child what they need so they can learn and continue to be successful?" In some cases there's a social worker that might help with filling out a form, a letter for home and hospital service, for example. In other cases that might fall to a child life person. Or the oncologists, the treating provider may fill out the letter that says, "Yes, this child needs home and hospital." But beyond that, there's not a formalized support process for that.

Brandon Barrera: Do we happen to have data that show what percentage of families do without some of these programs that are available to them, just because they haven't been introduced to it. Do we have a sense?

Lisa Jacobson: This is a hard question. There is a group up at Boston, the school liaison program at Dana Farber, that have worked to survey Children's Oncology Group institutions, and ask whether they have a school liaison program. I don't believe those data are published yet, and it was very difficult in talking to them, it was very difficult for them to actually acquire those data in a way that they're confident is accurate. We've asked our own providers here at Johns Hopkins, do you have a school liaison program, and some of them say yes, and they don't, and some of them say no, and
there's just some confusion around what does that mean, and if I, as a provider, can ask someone in child life to fill out a form for the family or to help the family access home and hospital services during treatment, is that a school liaison program? Is that enough support? I think there really is grayness or confusion around what supports fall to whom. Who's the primary medical team side person? And is there a central contact in a given school or a school district that could help receive medically complex children?

Brandon Barrera: Speaking to that, in one of the research articles you shared with me, there was an emphasis placed on the role of the oncologist to do a better job of informing the parents and families of options that would be available to them. The argument, though, of the article seemed to be that there is a unique opportunity for oncologist offices to step up in this capacity. Some other areas that were identified, it almost seems like it's a village, it takes a village to look after these families or to make sure that we have the best possible outcome for survivors. You mentioned the medical teams, you mentioned the school environment, there's the home environment. In a perfect world, what would you see the oncologist office change or offer?

Lisa Jacobson: That's a good question. In a perfect world, I think what we have learned from parents of survivors and from providers is that repeated conversations are important. So families need to know early and often what the educationally relevant late effects are likely to be. If those conversations happen repeatedly, then the providers will be a little bit more aware of any difficulties that the child is experiencing, that the parent is reporting. The parent will then be able to ask for help. Can you point me to a neuropsychologist? Can you point me to someone to help me with paperwork related to school re-entry? I think that is one of the biggest changes in a perfect world that I'd like to see is repeated conversation.

Lisa Jacobson: Parents have said, "Well, I think they told me when my child was diagnosed, but I had so much going on, I couldn't hear it. I'm only worried about will my child survive. I'm not worried about late effects of treatment that will happen a year from now or three years from now or 10 years from now." So if we have those conversations more, the providers are willing to ask those questions every couple months, periodically, it doesn't have to be every visit because sometimes the visits are every week, then that will raise the conversation so that people can hear it and it will normalize it. Yeah, this is something that we check in on because this is important for outcomes and for quality of life. Then I think the other component is, as you alluded to, it does take a village, but it has
to be a village of people who know their roles. So if it's everybody's job, then it's no one's job, and it can be really difficult when providers or teams aren't quite sure who is the go-to for this particular piece.

Lisa Jacobson: Our group is doing a couple of different things to try to address some of that, to try to equip families and providers. One thing we've done is literally apply for grant funding to develop a school liaison program. It's the Hospital Education Liaison Program, so HELP. HELP services are really designed to help families make that transition, take the neuropsychology results, understand what it means, and help translate it for schools. Here's what my child needs. So there's somebody to help them. But again, grant funded at this point. Another thing that we've done is create a massive open online course, a MOOC, on Coursera, that's called "Kids with Cancer Still Need School" for providers. And that helps raise the awareness for providers about some of these challenges that are related to this return to normalcy, go back to school kind of transition that can be challenging.

Brandon Barrera: Are there safeguards in place to prevent the worst of not addressing these needs? If we don't address properly, then what can develop down the line?

Lisa Jacobson: What we know is that high school graduation is really important. It opens doors that not obtaining a diploma or a GED doesn't. So employment, income, living independently, being able to support yourself, your family, these things all depend on getting an adequate education. And we also know that if you get supports like special education... There was a paper that came out quite some time ago now that showed that survivors who receive special education are more likely to graduate at rates approximating their siblings than survivors who did not. So this idea of actually getting the help you need so that you can graduate so that it opens doors for you down the road. And we know that education is a social determinant of health. So that will in the grand long scheme improve health overall. These children already are going to have health challenges their whole lifelong, but being better educated can help us take better care of our health.

Brandon Barrera: We’re discussing so far the realities faced by survivors during normal pre-COVID times. What happens when you add a global pandemic to the mix, to your day to day?

Lisa Jacobson: Something that we've learned from our COVID experience is that even when there are support systems in place, during times of challenge or stress, those may not be adequate. They may fall apart. So we actually
surveyed, we met with several of our families, we did some qualitative interviewing, and then we sent out a survey to just over 50 families of survivors and asked them, "How did school go in the spring of 2020 and the fall of 2020? Was your child supposed to be getting accommodations or special education or related services like OTPT speech? And if so, did they get them, those services that they were entitled to receive?" And what we found is that of those families who said my child was supposed to be getting these, just over 50... Sorry, just over 30% reported that their children were actually receiving some form of services, even if that was a conversation with the parent about how the child was doing or an online session much less frequently than it would have been in person.

Lisa Jacobson: So there's a real drop. There's a real concern there. The other thing that we found related to COVID was that many of our survivors experienced new challenges because of online schooling. So if you have an optic pathway tumor and it affects your vision and your ability to take information in, and all of a sudden you're having to navigate a website to find your homework assignments and click on all these little things, it can be really hard. So there are pieces about learning online that maybe unmasked or showed more difficulty that some of the survivors were having that maybe hadn't been noticed before.

Brandon Barrera: You published a white paper titled "Learning from Children with Cancer". Did this period present an opportunity to perhaps pull some lessons or approaches that we can apply to other areas of education?

Lisa Jacobson: One of the things that we were thinking in that white paper was this isn't just about cancer. This is about any children that have chronic illnesses or medical conditions that cause them to miss school, feel unwell, require adjusted instruction in some way. So what can we learn from the COVID experience, given that it's a strong possibility going forward that those kinds of children and their families will receive their instruction online? You can't go to school. No longer, maybe, will we be sending a home and hospital teacher to your house. They may do that via an online delivery of Zoom or GoToMeeting or whatever. So it's a real open question as to what additional supports will be required for any child who tries to access school remotely due to medical reasons or vision concerns or hearing concerns. How do we accommodate those well? How do we provide the assistive technology and educate school teams, educate families to ask for it, to understand what the options are, and help everyone to really be able to consider the landscape of needed supports, and then making things as accessible as possible.
Brandon Barrera: In the time that we have left, I'd like to explore a little bit of the work that you do also with the Kennedy Krieger Institute Center for Innovation and Leadership in Special Education. Educators are also an incredibly important piece of this. Personally, I just can't thank teachers and lifelong educators enough, partly because sometimes they have to deal with students like myself. But especially during this pandemic, we've seen how much falls upon educators' shoulders. Could you tell us a little bit about the resources you provide through the Center for Innovation and Leadership in Special Education? Some of what the mission is?

Lisa Jacobson: One hundred percent. Teachers are amazing and they've had quite the year, just as everybody else. They're multitasking and really trying hard to do amazing things. So hats off to them. One of the things that we know, though, is that even in the best of times before COVID our teacher pre-service education programs don't always equip teachers in all the ways that they need to deal with children who learn differently. Children who have neurodevelopmental disabilities, who are fully mainstreamed, who are in a regular education classroom may or may not receive special education, may not be that significant that they've been identified yet or ever. So how do we help in service teachers, teachers who are teaching these students now, better do that, better understand the learning challenges, the specific characteristics of various disability, like reading disability or math disability, ADHD, some of these high incidence that are going to be in most classrooms.

Lisa Jacobson: So that's part of the mission is to increase the knowledge base around those kinds of neurodevelopmental disorders, increase their ability to understand law and policy and administrative finance, how decisions get made at the policy level and how special education and regular education law impacts the way that we do business in schools these days, but also consume research. So we're not trying to make researchers, but we're trying to help teachers become more savvy consumers of educational relevant research. Does this study apply to my students? In what way? If we have a big push to utilizing evidence-based strategies, how do I evaluate the evidence to know if it's the right strategy for my classroom or for my student group? So that's the overall mission of that program.

Brandon Barrera: It sounds like should teachers, then, be reading academic journals regularly? And is there a pay wall involved or do these resources exist at much more accessible levels?

Lisa Jacobson: I think the answer is most teachers don't have time or the ability to access academic journals. You mentioned a pay wall. If you're not enrolled in an institution like an institute of higher ed, a university, a
master's program, something like that, it's very difficult to access. And what we know is that the soundbites you hear online or on the news aren't always 100% accurate. So what we've tried as a function of this program, the center, is we've launched a blog, and hats off to Dr. Lisa Carey who has really, really pioneered this. There's a Linking Research to Classrooms blog, and we've interviewed experts, we've reviewed papers, we've done a digital resource roundup for various topics and distilled some of the evidence so that there are accessible, readable, quick ways to get research out on particular topics.

Lisa Jacobson: Sometimes it's around a particular disorder, for example, pediatric cancer month. Sometimes it's around new resources. So when COVID hit, we switched that blog to be a little bit more available for both parents and teachers in topic selection and said, "How do we support online learning? How do we support attention and executive function for all students learning online?" And trying to share out ideas and resources that way.

Brandon Barrera: Final question. Some of what we'd like to do on the show here is not only present brain research or the topics that neuroscientists are researching and looking into and discovering, but also have a chance to speak with scientists that are interested or who find value in doing outreach. From the work that you do, what role do you see outreach playing in your work?

Lisa Jacobson: I think it is and will be huge. I think of outreach in multiple different ways. So we've developed infographics to send out that have a snapshot of information for parents or a different one for providers. I mentioned the MOOC, the online course to think about how do we get pieces of critical information out to the people that need it, whether that's providers, again, or families. Our HELP program, the school liaison program is really about trying to help get information out to schools as well. One of the things that we've applied for new funding for is to do a school-based education component in relation to students. So if you're a receiving school, we want those teachers to feel like they have a working understanding of what's going on. The Center for Innovation and Leadership in Special Education is launching an online version, a sort of a blended curriculum PBC to allow teachers from all over, potentially, to be able to access, to be able to scale up that program. So I think it's really going to be critical in all directions.

Brandon Barrera: Wonderful. Dr. Jacobson, thank you so much for joining us. Where can our audience follow you or go to learn more about your research? What would you like to communicate to listeners?
Lisa Jacobson: I can send people to the kennedykrieger.org website. That's the Kennedy Krieger Institute's website. We have an oncology clinic website where the resources, return to school roadmaps, and the blogs are posted. The center for innovation and leadership webpage is also on the kennedykrieger.org website. And we also have a lab Twitter @SuccessLab3.

Brandon Barrera: Wonderful. We'll have all those links in our show notes. Once again, thank you so much for joining us, Dr. Jacobson. And to our audience I say thank you for joining us. If you'd like to find any more neuroscience resources and articles, please visit us on Dana.org. This is Brandon Barrera saying stay tuned, 'till next time.