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Welcome to the Eye on the Cure Podcast, the podcast about winning the fight against retinal disease from the Foundation Fighting Blindness.

Ben Shaberman:
Welcome, everyone. This is Ben Shaberman, Senior Director of Scientific Outreach at the Foundation Fighting Blindness. Very glad you could join us for another episode of The Eye on the Cure podcast. I'm really looking forward to this particular podcast because this is for a technology that is truly cutting edge. At the Foundation, we're often talking about some pretty cool and innovative technologies like gene therapies, and stem cells, and optogenetics. Well, this is really the epitome of cutting edge technology. With us, today, are Philip Troyk, who is a PhD, and a professor in the Department of Biomedical Engineering. He's the Executive Director of the Pritzker Institute of Biomedical Science and Engineering, and an affiliated professor in the Stewart School of Business at the Illinois Institute of Technology. What he and his colleague, Dr. Lane, will be talking about, Frank Lane, is the Intracortical Vision Prosthesis.

So, let me tell you a little bit about Dr. Lane. He is a PhD, and an associate professor and associate chair in the Department of Psychology at the Illinois Institute of Technology. He joined IIT in 2006 as a faculty member and Director of the Rehabilitation Engineering Technology program. I would say that Dr. Troyk is really focused on the technology side of this Intracortical Vision Prosthesis. Then, Dr. Lane is really focused on the patient and the clinical side. Dr. Lane has a long history of working collaboratively with the Chicago Lighthouse where this trial will be taking place. He and Dr. Margaret Huyck, Professor Emeritus, began conducting focus groups at the Lighthouse in 2008. The purpose of those focus groups was to determine the perspectives of people who are blind about the restoration of what he calls visual percepts. So, to get us started in talking about this, again, very cutting edge device, the Intracortical Visual Prosthesis, Dr. Troyk, will you tell us, first, what the visual cortex is for those of us who don’t know, and then, what the prosthesis is?

Dr. Philip Troyk:
Thank you, Ben. It's great to be here, and I'm very happy to tell your listeners about this project, which we've been working on for over 20 years. The vision cortex is the region of the brain that receives the input from the optic nerves, which, of course, receives it from the retina. So, light comes into the eyes, stimulates the retina, the retina produces nerve impulses, they travel up the optic nerve, they stop off at place, and they eventually get to what we call the visual cortex. So, if you put your hand in the back of your head just above your neck on both sides where you feel your skull kind of bend down, that’s where the vision cortex is. You have one of those on each side. That's called the occipital lobe of the brain. So, that's where all the input from the optic nerve ends up going, and that's where your brain figures out what it is that your retinas are detecting from light that's coming in.

Vision, of course, isn't a little TV tube in your head. Vision is your brain decoding all these neural signals, and creating the perception of what the image is in your brain. So, something like the Intracortical Visual Prosthesis is one of a number of vision prosthesis devices that attempts to technologically interface with the vision system at different levels. You could go to the retina. You could go to the optic nerve. We’re going to the brain. The idea is you make a technological connection to the visual part of the brain, the occipital lobe, which has the vision cortex, and then you put electrical signals in, which are controlled by a camera. The camera senses the visual environment. Through processing that we don't fully understand yet, it converts the image information into electrical signals that we use to stimulate the vision cortex.
The idea is, we stick this vision information directly into the brain, bypassing the eyes and the optic nerve.

Ben Shaberman:
Right. I think that's a really important point for our listeners. When we think about treatments, obviously for retinal diseases, usually they're applied to the eye and the retina. Even the artificial retinas, the prostheses out there, right now, mostly are going into the eye and are attached somewhere near, or underneath the retina. This is bypassing the retina and the eye entirely, which is pretty amazing. What is, exactly, or what will be going into the person's visual cortex? What's the hardware?

Dr. Philip Troyk:
So, to make this interface to the brain, you're correct, we have to have a hardware system, a technological way to introduce these signals into the brain. That's done by putting very tiny, miniature electrodes that go into the brain. When small electric currents go into them, it then stimulates the neurons that are in the brain. Then, the brain starts reacting the way it would if it receives signals from the optic nerve. To do this, we have what's called the Intracortical Visual Prosthesis System, or ICVP for short. The system uses these tiny implantable modules that go onto the occipital lobe. These little modules are called wireless floating micro electrode arrays. They're about the size of the button that you feel on the top of an AA battery. They're very tiny, but each one contains 16 miniature electrodes that penetrate the brain. They penetrate the brain to about a depth of 10 thicknesses of paper so somewhere around one to two mm. Each electrode has a very, very small tip. You could put 10 electrode tips on the tip of a human hair. That's how tiny they are.

Ben Shaberman:
Wow.

Dr. Philip Troyk:
They come out from this tiny disc that's about the size of the button on the AA battery. In that little disc, is electronics, and it's wireless electronics. It can be powered and communicated with wirelessly.

The way it works is kind of like a little cell phone network in your head. So, each of these little modules, the wireless floating micro electrode array, or WFMA as we call it, it has an address like an area code with a telephone number. Each electrode, in there, has an address that's like a phone number. So, wirelessly, from the outside of the head, with no wires crossing the scalp, or nothing mounted directly into the head, some systems have an electrical connector, this does not, we can power these. We can call up any electrode, and tell it what to do.

You could put about 40 of these over the surface of the occipital lobe. You could get 600 to 700 electrodes that you could place, there. The idea is that by capturing the scene with the camera mounted on glasses, translating that scene into commands that tell the electrodes what to do, we hope to be able to create the perception of an image in the person's brain without the need to have eyes, or optic nerves.

Ben Shaberman:
Wow. That's quite amazing. You've been working on this technology for at least two decades, if I understood correctly from-
Dr. Philip Troyk:
The roots of the project actually date back to the National Institutes of Health in the 1970s. We inherited the project starting in 2000. Since then, we've been working to mature the technology to bring it to a point where it could be safely, surgically implanted in volunteers. Then, we would be able to start understanding how we can talk to the brain. Getting the devices in is step one, but then we got to figure out what to do with them.

Ben Shaberman:
Right, right.

Dr. Philip Troyk:
This is the exciting part. I'm an engineer, and I feel pretty excited about developing the technology to put them in. Once they're in, now the visual psychophysics have to take over, and they have to work with the volunteer. We have to figure out how we can communicate vision information to the brain. It's a very pioneering project, and we're very enthused. The whole team of people from eight institutions is extremely dedicated.

Ben Shaberman:
Right. So, eight institutions involved in the development of this device, and the trial. So, Dr. Lane, let's talk about this trial. I guess it's a very exciting time because, all this work over the decades, you're finally ready to start evaluating this system in people. So, Dr. Lane, who would you say the best candidates for the trial would be?

Dr. Frank Lane:
That's a great question. It's one that we've been working, as you say, over 10 years, trying to answer just that question of, "Who is a good trial candidate?" When you mentioned about the work that I did with Dr. Margaret Huyck, we started, or my portion of this started in 2008 when Dr. Troyk and I were working on similar projects, but both working with people who are blind. He told me about this project, and said that one of the questions that he had is, "Why would someone participate in having a neural implant implanted?" So, we said, "We don't know the answer to that question, but we'd certainly like to." So, what we did was conduct a series of focus groups at the Chicago Lighthouse, which then went from there beyond, into speaking with participants and individuals from other clinical trials to understand their experiences.

What we found, in our searching for the answer of why would someone participate, is that most individuals have a desire to participate in a trial like this for some sort of visual restoration. In other words, some individuals have very realistic, but others have unrealistic expectation. Clearly, everyone is wanting to restore vision. What we didn't anticipate we would find is that individuals have an altruistic motive, in that they would like to participate in groundbreaking research because it could help a family member, other individuals who are blind, or vision science as a whole. So, what we discovered was that these motivations, if you will, transcended not only focus groups, but also studies. We spoke to individuals in eight different countries who had participated in a vision clinical trial. So, the first thing that we've discovered is someone who's really interested in looking at this motivation as altruism, to try and help vision science.

As far as other candidates, I'd like to just go down and talk about some of the inclusion criteria that we have for the project that really sort of identify who those individuals are. Individuals should be 18 to 70
years of age, and have no light perception. That means the individual can have no light perception. If they can see a hand motion in their visual field, the individual would be considered unqualified for that. They have to have a history of near normal vision, at least to the age of 10. The reason for that is because the belief is that it takes that length of time for the visual cortex to sufficiently develop to be able to respond to the implant itself. It's also important that the individuals we work with are adjusted to blindness. That part of that adjustment to blindness, and evidence of that, is history of engaging in blindness rehabilitation like white cane training, independent living skills training, things of that nature.

We also found that it's important for participants to have a really strong support system. That support system varies from individual to individual, friends, family members, participants in their healthcare such as physicians, clergy. All of these individuals make up a support system that we feel is important for good participation in the trial.

Ben Shaberman:
Just to clarify, this trial will be taking place in the Chicago area?

Dr. Frank Lane:
Yes. It will.

Ben Shaberman:
And, you're recruiting how many people?

Dr. Frank Lane:
Recruiting a total of five individuals.

Ben Shaberman:
Five people. Okay. In the Chicago area. I want to get back to a word that Dr. Troyk used because I think it's really important to emphasize. That's the pioneering aspect of this trial. I know, when people in our world of retinal diseases go into a trial, they're hoping to have some meaningful vision restored. There's a certain expectation, perhaps, if the treatment works, what people might see. In this trial, if I understand correctly, things are a little different. Maybe, you can elaborate on this, Dr. Troyk, or Dr. Lane, or both of you.

Dr. Philip Troyk:
Sure. I'll jump in, and let Frank give his thoughts, too. So, yes, indeed, it is experimental. It's experimental because, frankly, nobody knows exactly how to talk to the brain artificially. Nobody knows exactly how to convert information from a camera to be meaningful when it's perceived by the person. So, in that respect, it is, as we like to think of it, almost as pioneering as astronauts going to a place where humans haven't been. So, the participants in our project, and we like to call them participants, not patients, because they really are members of our research team. They'll have to be because they will tell us what's happening when we try to do this artificial stimulation, but we wouldn't be doing it if we didn't think there was a likelihood of some benefit. What we've also found, and others have found, is that for someone who has no light perception, at all, an even minimal amount of vision information can be very helpful to tell the difference between day and night, to be able to see things moving in their vision field.
One individual that Dr. Lane interviewed, who had an earlier system, from a different group, had nine spots of light. When you stimulate, you get these spots of light that are called phosphenes. With these nine spots of light, he was able to see the edge of the curb. He was able to navigate more easily to a job that was further away from his house than he ordinarily could have. That was a meaningful perception for him. He didn't see his child's face, but he had artificial vision in a way that improved his quality of life. So, we don't know where the system will lead us, and we don't know what these experiences of these five people will define for the next generation of devices. That's really why our enthusiasm is so high. We're looking for people who have similar enthusiasm and want to contribute to knowledge, and want to help the field advance so that one day such devices will become routine care.

Ben Shaberman:
Right. So, really, the candidates for this trial have to be really more interested in helping you, the researcher, than, perhaps, gaining significant visual benefit. They're helping you understand what's working, maybe what needs adjustment, and what the potential vision restoration might be.

Dr. Philip Troyk:
Of course, we all have hope. We have hope of the aha moment-

Ben Shaberman:
Right.

Dr. Philip Troyk:
...when we do discover something that, then, allows even the limited technology that we have to be more useful to the person than we might have even anticipated.

Ben Shaberman:
Right. Dr. Lane, I don't know if you have anything more to add. One question I definitely have is, tell us who would not be a good candidate for this trial.

Dr. Frank Lane:
Certainly, someone who recently lost their vision, say within the last year, and someone who hasn’t had sufficient time to adjust to being blind. In our research, we've found that individuals who aren't well adjusted tend to have unrealistic expectations of what the device can do. When that expectation isn't met, there's disappointment, and often negative emotions that are associated with that. Certainly, if it's someone who, for whatever reason, there's something interfering with their decision making capacity, individuals who have a history of seizures. There are also some other health related conditions that would make someone not a good trial candidate. I would say that those are the primary ones.

Ben Shaberman:
Right. I'm sure this doesn't show up in the clinical trials' inclusion or exclusion criteria, but I think somebody has to be pretty courageous to get involved, and go through the surgery, and move forward from there.

Dr. Philip Troyk:
Courageous is a good word, and dedicated is also a good word because it will require time commitment. We will have to be working with the recipients of our system over an extended period of time. The whole trial runs for three years, and the five people will be implanted at different times in the trial. So, the very first person will have three years of experience with us. It will require dedication and patience. Yes. We're not looking for superhuman people, in that respect. I think, maybe, Frank can comment on it, another thing his work brought out is that individuals who are interested in this also have a strong sense of adventurism. They'd like to do something somebody else hasn't done before. Ironically, to do that, the person has to be visually impaired.

The FDA has approved us to implant this in individuals with blindness, but they haven't approved it for implantation in people who have near normal vision. So, we actually need individuals who have the ability, not disability, the ability to tell us because they are visually impaired, how we can do this interface to the brain. If my enthusiasm is coming out in this it's because we're adventurous, too. We're very enthused about seeing where this can take us and the field.

Ben Shaberman:
Exactly.

Dr. Frank Lane:
The little that's been written about motivation to engage in pioneering research is that principal investigators, we're all motivated by this pioneering kinds of research. So, why is it that the participants in our study couldn't be equally as excited as we are and participate in the clinical trial at a similar level in terms of both.

Ben Shaberman:
Right. So, Dr. Lane, can you tell our listeners, if they're feeling adventurous and pioneering, how to reach out to you, to inquire about the trial?

Dr. Frank Lane:
Oh, of course. So, there are a number of different ways that individuals can reach out to us. One is by email. Our email address is icvp, for Intracortical Visual Prosthesis, @iit.edu. That's icvp@iit.edu. Individuals can also call us at area code (312) 567-5304. You can also see the proposal itself on clinicaltrials.gov. If you'd like to see the main homepage for the clinical trial, it's chicagolighthouse.org/icvp. At that particular site, there are audio files of prior educational sessions that individuals who would like to learn more about the device can hear, and also, questions that other attendees at those sessions asked, and the responses to those. So, a lot of very thorough information on the website, certainly for someone who's interested in learning more, and certainly direct contact with us if you have specific questions.

Ben Shaberman:
That's great. Thanks for all that contact information. I'll remind our viewers, if you have questions about this podcast, or any podcast, you can always send an email to podcast@fightingblindness.org. It's probably better, if you have questions about the prosthesis, to email or contact Dr. Lane's group through the information he gave you. Feel free to reach out through the email address podcast@fightingblindness.org, as well. One question I had to kind of wind things down, here. I suspect when you're a kid, even in school, you don't think about being involved in projects like this. How did you
Dr. Philip Troyk:
Go ahead, Frank.

Dr. Frank Lane:
So, mine really goes back to going to graduate school. I chose a PhD program that worked with candidates on learning how to do cross-disciplinary research. I came out of school looking for individuals from other disciplines to do work with. IIT, as an engineering school, turned out to be a really good place for me and my interest in technology because I feel strongly that participants, people who are blind, should have a strong voice in the research that we conduct. In very early conversations with Dr. Troyk, that resonated for him. That was really my entrance into this project, and what really has been some pioneering work that I didn't anticipate on my end, but is certainly the kind of thing that gets me out of bed.

Ben Shaberman:
Thank you. And, Dr. Troyk.

Dr. Philip Troyk:
Well, it's funny because you made mention of when you're a kid you don't think about working on something like this. I guess, I was from the group that they called nerds. Right? I can tell you that, from as long back as I can remember, electronics fascinated me, and there was never any doubt what career I wanted to have. I didn't have to go through a discovery process in grade school, high school, or even at the university. I just knew I wanted to do electronics. Probably the bifurcation point was when I began to understand that our bodies work primarily by electric signals that control every function of the body. I began to think, "Why can't electronics be married with the body?" From that point on, my career trajectory was just deeper and deeper into how to interface electronics with the body. To me, it just seemed like a natural extension of everything I had always thought about. It's really a labor of love. It's not a career, it's just what I do.

Ben Shaberman:
Right. So, when you were a kid, did you hang out in Radio Shack quite a bit?

Dr. Philip Troyk:
Well, actually when I was a kid, Radio Shack was called Allied Radio. They used to send catalogs in which they had kits called Night Kits. So, there was Night kits and Heath kits. You'd look through those catalogs like a Christmas wishlist, thinking what you could get. Yes. Actually, it's funnier than that. My friends in the neighborhood and I, who were similarly interested, we used to scrounge along the railroad tracks near the house for old TVs that people used to throw. We'd cut all the parts out of them, and then use them for other projects. So, when I said it started young... I was a nerd when I was a kid, and I guess, I still am.

Ben Shaberman:
Well, those are great stories, and we're grateful for your nerdiness. We need that to move these technologies forward so thank you. Dr. Lane, Dr. Troyk, thanks for a really fascinating discussion about this emerging device, and your clinical trial. Again, they are recruiting. You can send an email to icvp@iit.edu if you're interested in learning more about the trial from these gentlemen. Or, you can call (312) 567-5304. Thank you, again, gentlemen, and thanks to our listeners for tuning in to another episode of Eye On The Cure. Hurry back for the next episode in a couple of weeks.

Dr. Frank Lane:
Thank you.

Dr. Philip Troyk:
Thank you for having us, Ben.

Ben Shaberman:
Thank you.

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This has been Eye on the Cure. To help us win the fight, please donate at foundationfightingblindness.org.