A CommunicationFIRST Webinar

Brain to Text Technology?
¿Tecnología de Cerebro a Texto?

A Conversation on Groundbreaking AAC Research
with Board Member Pancho Ramirez and
University of California San Francisco (UCSF) Neuroscientists

October 19, 2022

Transcript

[TAUNA SZYMANSKI]: Welcome, everyone, to today’s webinar on Brain to Text Technology. Before we begin, we need all participants to select a language channel. The selection process is different depending on whether you are tuning in on a
computer or a mobile device. I’m going to share my screen now so you can see a visual of these instructions. So, one moment.

All right. If you’re on a computer, click on the globe icon along the bottom of your screen and select your language. If you’re on a mobile device, click on the three dots in the corner of your screen, select Language Interpretation, and then choose your language, and click Done. Do not select “Mute Original Audio.” Again, all participants need to make a selection even if your preferred language is English. Ernesto, can I please invite you to provide these instructions in Spanish?

[SPANISH INTERPRETER]: Yes, thank you, Tauna. Buenos días, buenas tardes. Para escuchar la interpretación al español en su computadora, haga clic en el icono del globo terráqueo en la parte inferior de la pantalla. Luego seleccione “español.” En un dispositivo móvil, sea tableta o celular, haga clic en los tres puntos en la esquina de la pantalla, luego seleccione interpretación de idioma “Language Interpretation,” elija español y no olvide hacer clic en “Done” o finalizado arriba a la derecha. No seleccione silenciar audio original y se copiarán estas instrucciones también en el chat. Thank you, Tauna.

[TAUNA SZYMANSKI]: Thank you, Ernesto. All right, so please be sure to select your preferred language now before we move forward.

Okay, welcome to this webinar on Brain to Text Technology. My name is Tauna Szymanski, and I’m the Executive Director and Legal Director of CommunicationFIRST, which is the only civil rights organization that seeks to protect the rights of and advance the interests of the estimated 5 million people in the United States who cannot rely on speech alone to be heard and understood regardless of disability or condition.

I’m a white woman in her forties with brown hair. I have a wonky left eye and I’m wearing glasses. We’re thrilled today to have our Board member Pancho Ramirez, and the team of neuroscientists at the University of California San Francisco, who are working with Pancho to develop cutting edge technology that could become a game-changer for people who need to rely on augmentative and alternative communication or AAC due to motor-based speech disabilities.

There are several movies and articles that provide background material about both Pancho and the research study that are on our website, and I encourage you to
check them out if you haven’t yet. Ren, I'm going to ask you to put the link to that page in the chat when you have a moment. Thank you.

Today we’re offering simultaneous interpretation in both Spanish and American Sign Language. We’re also offering live captioning, or CART. To turn on the captioning, please select captions or subtitles at the bottom of your screen. And we’d like to remind all of our panelists to include their pronouns and provide a brief visual description of themselves and of any slides they’re presenting.

Thank you to the registrants who submitted questions in advance. We received well over 50 questions and have done our best to consolidate them so that the panelists can address as many as possible, but we do apologize in advance if there isn’t time to get to yours. We do have the Q&A function operational, and you are welcome to comment there. But we may not be able to address all questions that are just being submitted today during the webinar, unfortunately, just due to time.

So I’m now going to turn things over to our Program Associate, Erika Prado, who will be moderating this webinar today and has done the bulk of the planning and organization on it, together with Pancho. Erika?

[ERIKA PRADO]: Hi everyone. My name is Erika Prado. My pronouns are she, her, hers. I’m a Latina with light colored skin and long dark brown hair. I’m wearing glasses and a white shirt. I’m very excited to be introducing our presenters today.

First, we have Pancho Ramirez. Pancho is a Board member for CommunicationFIRST. At the age of 20, he acquired his speech disability after a car accident that led him to a brain stem stroke. While living in nursing homes, Pancho has taught himself English, earned his GED and a web developer certificate, has taken college courses, started learning French, and has become a key member of a research team at the University of California San Francisco that is developing groundbreaking communication technology.

His contributions have been featured in many research articles and also in an article for The New York Times. Pancho’s contributions to communication technology are undeniable, but I just want to say that Pancho is an extremely kind, funny, humble, hard worker, and we are very lucky to have him with us today.
Next up is David [Moses]. David is a senior postdoc in the Chang Lab. For his PhD in the same lab, he developed tools to turn brain activity into words in real time. Now he manages and coordinates clinical trial projects aimed at translating this technology to people who do not use speech.

Jessie [Liu] is a graduate student researcher in the Chang Lab. Her educational background is in bioengineering, and she works on speech BCI, and projects to understand how the brain controls how we speak.

Margaret [Seaton] is a clinical research coordinator in the Chang lab. In the lab, she coordinates patient care needs and trial management for several clinical trials.

Max [Dougherty] is also a clinical research coordinator, working both on patient care and development of software tools to enable real-time feedback.

So for the agenda today, we will first hear from the UCSF researchers, who will be going into further detail about the technology itself as well as the goals of the clinical trial. [CommunicationFIRST Policy Director] Bob [Williams] will then give some remarks about Pancho, as well as general lessons about challenging assumptions about people who don’t reliably produce speech.

Then we will hear from Pancho and his experiences as a pioneer in the clinical trial research projects at UCSF. And lastly, Pancho and the research team will be answering questions that were submitted in advance. And if audience members have any questions throughout the webinar, please type them in the Q&A box, and if we have time at the end and the panelists are willing, we will try and get to them.

So without further ado, I will now pass it on to the UCSF researchers who will try and explain to us in easy-to-understand terms what this technology is and what it might mean for our community in the future.

[MARGARET SEATON]: Hello, everyone. We’re going to pull up some slides for you guys to see.

[DAVID MOSES]: We’re excited to be joined here by the legend himself, Pancho. So you’ll hear from him shortly, but we’ll get started on with our slides soon.

[MARGARET SEATON]: Okay, want to start with the introduction? Oh.
[DAVID MOSES]: Oh yeah, sure. So I’m David, I’m a postdoc. Go by he/his, and I have curly hair. I’m a male in my thirties, so it’s nice to really, it’s a great honor to be able to present our updates and to try to explain, you know, what we’re working on with Pancho here. And I think we’ll get started shortly, but just a brief overview is that we are part of the BRAVO clinical trial, which is aimed at developing brain-computer interface technology, so that persons who struggle to communicate naturally through speech can actually use this technology to simply try to speak and then have their intended messages translated directly from brain activity and shared with others. So we’ll let Margaret get started.

[MARGARET SEATON]: All right. Hi, everyone. So happy to be here. My name is Margaret Seaton. I use she, her, hers pronouns. I’m a white woman in my twenties. I have blonde hair. I’m wearing a black shirt and a mask – yellow mask. So good to speak with you all.

I’m going to give a little bit of background to start out just on brain computer interfaces in general, because we’ll be using this as kind of the kickoff point for the rest of the presentation. So I just want to make sure everybody understands what we mean when we talk about brain computer interfaces. So brain computer interface technology uses directly recorded neural activity from the brain and decodes it into commands, which would allow for control of various devices or the environment.

And so it can be any sort of output, but the large thing with brain computer interfaces is that it doesn’t require any motor input. It comes directly from the brain. So communication-based BCIs, which is what we will be talking about for this presentation, have the potential to restore movement and communication capabilities to individuals with impaired speech and movement due to a variety of neurological causes to improve interactions with technological devices and with the environment.

They also have the potential to meaningfully improve future user independence. And that’s really the thrust behind our entire project, is to hopefully improve independence for users in the future.

[JESSIE LIU]: Okay, we’re switching speakers now. So, [laughs], I’m Jessie. Like Erika said, I’m a graduate student in the Chang Lab. I use she, her pronouns. I’m 27 years old. I’m an Asian woman with dark hair, wearing a jean shirt and also a yellow mask.
So we talk a lot about signals coming from the brain, and we also wanted to explain a little bit more in detail what we mean by that.

So really our brains are acting kind of like a control center. And when we refer to the term “cortex,” that is just talking about the outermost layer of the brain, which is where we record from. So you probably might be familiar with [the fact] that different parts of your brain control different parts of your body, and they help you do different things.

So for example, you can have the visual cortex, which is helping interpret what our eyes see. You also have the temporal lobe, which is playing a role in understanding what we hear. And so that helps us understand speech. And then also kind of broadly you have [the] motor cortex, which is helping us control voluntary movements.

So this can be like moving your arms or moving your mouth to speak. And so this is the important part that we really focus on. This is what’s called [the] speech motor cortex. And it’s these signals that we’re really leveraging for our research.

And so we’ve been able to learn a lot about speech motor cortex by working with epilepsy patients. Epilepsy patients are in the hospital and have their brain activity recorded for other medical purposes. So while they’re doing that we can also record that data and have them do some experiments with us, without increasing any medical risk that they’re facing.

So working with them has helped us map this part of speech motor cortex that controls our face. And different parts of this speech motor cortex also control different parts of your face. So, there’s a bunch of red dots on the screen just illustrating one part of it that helps control lip movements, for example.

And so all of these patterns are different enough that we can use them to predict what a person said out loud, so predicting like an audio file of what they had said. Or we can also predict it as text on a screen. So, if somebody says hello, you could print hello on the screen just based on their neural activity.

But of course this is all with people who can speak normally. And our core purpose is extending this work to patients who need the technology. So if a person with Locked In Syndrome-- so just somebody who isn’t able to use the muscles in your
face to get out the speech you want, would we find similar patterns in [the] motor cortex? That’s been a key question in our research. And if there are those representations, can we also still use them to decode the intended message?

So assuming that we could find it, we could develop something called brain-to-speech technology. So this can help us decode the brain patterns of someone who’s trying to speak, even if their facial muscles can’t execute those.

So, very generally, you would have some human users, someone in the loop, where you’re recording your neural activity. You would have some processing system that would take in that neural activity and then output the desired speech. So that could be an audio sort of file like I mentioned before, or it could be text on the screen.

And so that brings us to our specific trial. Our trial is called the BRAVO trial. It stands for the BCI Restoration of Arm and Voice. So this is jointly led by two different labs, Edward Chang’s lab, which is us, and also Karunesh Ganguly, who’s also at UCSF, that has a sort of separate effort. So we really focus on the voice part, the speech part, and we’re studying these neural representations of speech in people with paralysis. So people like Pancho.

And this is also to validate the safety and long term viability of this approach. We want to make sure that it could work for a long time and obviously that it’s safe to implant. And so our last goal is to develop a speech neuroprosthesis or a speech BCI that can help patients communicate.

[Max Dougherty]: Hi, I’m next. I’m Max. I, as mentioned, was the other clinical research coordinator. I am a 30 year old male. Pronouns, he, him, and I am blonde and do not wear glasses.

So, to achieve the goal of better understanding and decoding speech from the brain requires some serious effort from Pancho over here.

So in 2019, he was implanted with a sheet of electrodes, which you can see illustrated in this middle, lower image here, about the size of a credit card. And that sits on the surface of the brain over the regions that Jessie was talking about that are associated with the movement of the mouth, the vocal tract, and arms.
So each dot here in this middle image is representing a separate electrode measuring different activity in the brain. And that’s illustrated then here on the right, in this video.

So Pancho works, actually, most days of the week during recording sessions, and will often be connected to the computer for up to six hours during these days. And to do that we use this small device that’s shown in the left hand here, in this picture, that is then connected with this pedestal that then directly interfaces with those electrodes measuring that activity that you can see a sample of on the right here.

Now, one of the most fundamental challenges of this work is aligning this activity with the actions that Pancho is taking outside in the world and the things that he’s experiencing.

So to give you a sense of how complex a lot of this data is, we can see here the same activity now played out over time. And you see these complex squiggles, these lines of the traces from each of these electrodes kind of reacting to, or measuring, Pancho’s brain as he’s attempting to speak. So to do this, we have to measure each of these points on the order of about a thousand times a second, which is fast enough to capture the dynamic activity going on in Pancho’s brain.

But one fundamental challenge, if you look at how noisy this data is, how much stuff is going on here, is that even while sitting silently, the brain is actively firing, which makes it very difficult to isolate these processes where he is actually trying to speak from other things that are going on in his brain at the same time.

So to tackle that, we often have to take dozens of trials of the same words to get a better representation of what’s going on in his brain. So to illustrate that, here we have, Pancho is saying the word “bravo” about 90 times and we’re just looking at the activity of a single electrode.

But you can see, as we collected these samples over the course of several weeks, we get this stable representation in red of the average response when Pancho says “bravo.” And we can use these samples then to hopefully decode his attempts at speaking different words, because we get these different representations.

To speak more on that, David Moses will take over.
[DAVID MOSES]: All right. Great. So David, again. To reintroduce myself, I’m a-- in my thirties, male, with curly hair and a white mask. Okay. So, as Max mentioned, we have to find a way to interpret all of these really complicated signals. And so to do that, what we did is we trained what’s called machine learning models to interpret all of the signals that we’re recording from Pancho’s brain.

And so to start, Jessie, who spoke earlier, trained a speech detection model. And the goal of this model is to scan all of the brain signals as we acquire them and to determine when Pancho’s trying to speak purely from the brain activity. Okay. And then once we have this detected window, this brief time segment of brain activity that we think is associated with Pancho’s attempts to speak, then our other colleague, Sean, trained a model to take that time segment of brain activity and figure out which word Pancho was attempting to say.

And so right now we’re using a set of 50 words. And so this model takes in that time window of brain activity and then predicts how likely it was that he was saying each of the 50 possible words, that Pancho was trying to say each of these words.

And then finally you can use, kind of-- think of this as like an autocorrect feature, how if some sentences in English, or in whatever language you use, are just more likely than other sentences.

Because some word combinations make sense and some don’t. Such as, “Hello, how are you?” makes more sense than, “Hello, how are glasses?” Right?

So this is an example of just the various-- just one small example of the various combinations of the 50 words that we had, and how some make more sense than others.

And so we can capture that information and use it to improve the predictions that the rest of our models make. And so once we put everything together, we can get something that looks like this, where we have Pancho here who sees this prompt that says, “How are you today?” And then he is trying to respond with his personal response.

And you can see that the model is detecting when he’s attempting to speak and then interpreting and translating these attempts, the brain activity during these attempts, into words. Okay.
So that was kind of the first major breakthrough that we had with Pancho. But we didn’t want to stop there, so we wanted to, you know—Oh, let me show you all, actually, first before we move on, some of the example decoding results.

So these are the sentences that Pancho was trying to say, and this is what we were able to predict purely from Pancho’s brain activity without using any kind of model of language. And then when you include this language model, this kind of auto correct feature I described, then you get a pretty significant improvement in the results.

### Decoding results

<table>
<thead>
<tr>
<th>Target</th>
<th>Without LM</th>
<th>With LM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hello how are you?</td>
<td>You are you</td>
<td>Hello how are you</td>
</tr>
<tr>
<td>I need my glasses.</td>
<td>I need my thirsty</td>
<td>I need my glasses</td>
</tr>
<tr>
<td>Please bring my glasses here.</td>
<td>Please please my glasses good</td>
<td>Please bring my glasses here</td>
</tr>
<tr>
<td>Yes.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>What do you do?</td>
<td>What do you do</td>
<td>What do you do</td>
</tr>
<tr>
<td>It is comfortable.</td>
<td>Is it comfortable</td>
<td>It is comfortable</td>
</tr>
<tr>
<td>My family is here.</td>
<td>My family is here</td>
<td>My family is good</td>
</tr>
</tbody>
</table>

**Overall: ~75% accuracy at 15 words per minute**

And overall, we’re at about 15 words per minute on the small set of 50 words and at about 75% accuracy. And so, yeah, we all, I mean, Pancho was thrilled! We were thrilled, and we were like, how do we get to the next step though? Because obviously there’s a long way to go before this technology can be truly useful in a daily environment.

So there is a natural way to scale up to tons and tons of words, and one that’s already being extensively used in assisted technology, and that is spelling. And so we wanted to try this, but we wanted to try it with a twist. So similar to how, let’s
imagine you’re hearing someone say letters over the phone, but it’s a noisy phone line and it might be hard to hear individual letters.

So in a similar way, it might be hard to identify single letters in brain signals right off the bat. So instead, we had Pancho use the NATO alphabet. And so this helped our models as we’re exploring and, you know, just starting this endeavor into spelling technology from a brain computer interface.

We thought it’d be best to use this kind of more rich word set. So Alpha instead of A, Bravo instead of B, and so forth, and to do this-- Or Pancho tried just like before to say these words many times and then now he’s able to use it after, you know, a lot of weeks and weeks of collecting data with Pancho.

Now we have his quick demo here where we show him spelling out a response. So this is, Pancho is trying to say these words, Alpha, Bravo, Charlie, to represent letters. And the system is putting all this information together and decoding spelled sentences directly from his brain activity.

And so here we have Pancho. This was during the midst of the pandemic and right in the thick of it, really. And so Pancho was giving us, you know, a nice, [laughter] a nice bit of advice.

[PANCHO RAMIREZ]: [Hums]

[DAVID MOSES]: There you go. It said, “You all stay safe from the virus.” And so Pancho was able to spell that out just by silently trying to speak and having his attempts interpreted and translated from his brain activity.

Okay, so here are some examples. So if you only look at the outputs of the neural models, you get a lot of-- it’s kind of jumbled. There aren’t any spaces. But now you can include these advanced language models as well, and you can see the information is there.

So we’re able to extract enough from the signals that we’re recording with Pancho to then get at about 90% accuracy at six words per minute. But now with over a thousand possible words in the vocabulary, and we’ve seen that we can take this even further with larger vocabulary sizes.
So we think that this approach is quite promising. It might represent-- to us it kind of meets the minimum threshold of what we would want someone to be able to use with our system.

And hopefully we can, with some next steps, take it even further. So we want to show, obviously, as might be very important to some of you attending this webinar right now, we want to show that this can work for not just English, but many languages.

In addition, we want Pancho to be able to actually have a voice. So that when he tries to speak, an actual voice comes out and not just text on the screen, so that he can actually express himself more freely.

This point is just saying that we want to continue improving the neural implant hardware, and there already have been improvements even in the past few years. So this is a rapidly expanding area of research. And so we’re very optimistic that hardware will continue to improve over the next decade.

And of course, we want to make sure that technology can work for many people and not just Pancho. Because that’s one of the main important steps, to make sure that this can really help as many people as we can.

So thank you. This is a picture of our lab, a lot of us here. Not everyone works directly with Pancho. Only the lucky ones do. But, anyways, thank you. Stop sharing this screen.

[ERIKA PRADO]: Thank you so much, researchers. This is Erika. I will now pass it on to CommunicationFIRST Policy Director Bob Williams, who'll make a few remarks before turning things over to Pancho.

[BOB WILLIAMS]: Good afternoon. I am Bob Williams. I am a white man in my sixties. My pronouns are he, him and his. Today, I use a speech generating device mostly in my work. Like most who require AAC, I use a range of voices to express myself and live my life and have done so for all my life. I am thrilled to say a few words about today’s webinar and even more thrilled and eager to have listened along with all of you.
To this afternoon’s presenters, I cannot think of a better way to honor the heritage and tremendous 21st-century contributions of Latinx people than to be learning about the leading edge research Pancho Ramirez and his colleagues at the University of California at San Francisco are doing on brain-to-text technology.

Pancho, we are extremely appreciative of the time and hard work that you, Erika, and the folks from UCSF prepared for today and your presentation today. As you might recall, some of us from CommunicationFIRST met you on Zoom about a year ago. It was soon after The New York Times published the story on the project and the key role you have in it, not as a “research subject,” but, in my view, as a participatory action research investigator. Full stop.

I also have to say that, from the time we met over Zoom last year [to] today, the things about Pancho Ramirez that impressed me most have nothing to do with this project and everything to do with the full measure of who he is: his humor, his intellectual curiosity, sense of justice, and work ethic, all of which does honor to his upbringing as well as culture.

He is also an aggravatingly humble and understated person. I know. So, listen closely to what he has to say to understand his full import. I leave it to the panel to discuss the implications, trajectory, and time horizon of this research. But I think one of the immediate lessons we can learn from the work taking place is that science is not fixed. It is not stagnant, but a living organism that evolves with time and hard work, and sometimes, what we believe science has proven turns out to be wrong and incomplete for people with disabilities and other marginalized individuals and communities.

But human and civil rights stratifications are clear for people with disabilities and other marginalized individuals and communities. The human and civil rights ramifications are clear, which is [that] we cannot let others simply assume and act as if they know everything they need to know about who we are and what will eventually still be proven to be possible. So already this research is influencing, in subtle, but consequential, ways, how we frame and do the disability justice and public policy work we do at CommunicationFIRST. Erika, back to you.

[ERIKA PRADO]: Thank you so much, Bob. I will now pass it over to the pioneer himself, Pancho Ramirez, and hear about his experiences.
[MARGARET SEATON]: Hi everyone. It’s me, Margaret again, and I’d like to introduce you all to Pancho Ramirez, who’s sitting here to my left.

[PANCHO RAMIREZ]: [Vocalizes in greeting]

[MARGARET SEATON]: Pancho is a forty-year-old male, Mexican male wearing a brown hat, a white shirt, and has a blue mask on, and he’s very excited to share his story today with you all. I will be reading his words for him at his request, so I will share some slides with you all. Okay.

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: Hi everyone. My name is Pancho Ramirez. I am a Board member for CommunicationFIRST. It is an absolute pleasure to share my experiences with you all about this clinical trial. I have no experience giving presentations, so if there’s anything that doesn’t make sense or is out of place, I apologize beforehand.

I have to get someone to read my text and speak for me. I only recently got a speech generating device, but it sounds terrible. I don’t like it to be my voice, so I have asked one of my team members to read it for me.

At the age of twenty, almost twenty years ago, I had a normal life. I could walk, I could talk, I could do anything for myself. I used to work and provided for myself. I was a healthy, happy young man full of dreams and so much to look forward to. Unfortunately, fate had other plans awaiting, and my life was about to go to an unexpected direction.

In the month of June, 2003, I suffered a car accident that led to a brain stem stroke leaving me paralyzed and unable to speak. I’ve been living in nursing homes and hospitals in Northern California ever since. While living in nursing homes, I taught myself English, earned my GED, and a web developer certificate.

Then I got here as a participant in this amazing clinical trial.

I think my God put me on the road I am now. I believe that it is the best and most logical explanation of the story. I am in this clinical trial because He wanted me to be. I am very happy about that because somehow I’m being used by him and I get to contribute to help others who don’t speak to have a way to communicate as I will have in the coming future.
I have a couple of American friends, husband and wife. They’re like a second family to me. They knew I wanted to go to UCSF Hospital because I expressed my interest to them in the past. So they managed to connect me with a person who used to work at UCSF. She asked me for some info, which I sent to her.

Then we set up an appointment to go and see a neurologist there at UCSF. On July 14th, 2016, I had the appointment with a neurologist, Gary Abrams, who is pictured here, a very good doctor from UCSF. I was very excited about that because I was told that UCSF was one of the best hospitals in the nation and has the best doctors who specialize in neurology.

So I was really looking forward to it. My first thought was, “Oh, the doctor is going to want to keep me there at the hospital and do many studies until they figure out how to fix me. Oh, yes, finally!” Oh my goodness. I don’t know what I was thinking. It was a great dream, though.

When my sister, a friend of mine, and I entered the office to see Dr. Gary Abrams, he started speaking and doing some assessments. I had to send him a brain MRI before my appointment, and after a while he said, “I saw your MRI and I have to give you another disappointment. I know many people think we do miracles here at UCSF. I wish that was true, but unfortunately we are just doctors who are doing the best they can, like most doctors do. Look, I’m afraid my answer is not the one you wanted to hear, but I have to tell you anyway: my friend, there is nothing we can do for you.”

He went on and said, “The stroke you had was very severe. It damaged a great part of the brain, and consequently a significant amount of brain cells collapsed.” He was about to end the appointment when he talked to me about this clinical trial, which was about to start, he said, in the month of August. He explained to me a little bit about the study. He said that they may place an implant in the surface of the brain of the participant, and such [an] implant would be used to connect the participant to a computer system.

Then the computer system should collect brain signals transmitted by the device, and so people operating the system would be able to manipulate the brain signals, something like that. I will let the researchers explain this part. Anyway, he said that the purpose of the study was so the participant could, hopefully, control a robot arm.
I got so excited as soon as he mentioned that. I don’t even remember if he told me about the speech decoding part of the study yet, which was featured in an article published in *The New York Times* that some of you may have read. He asked me if I was interested in participating, and I replied, “Of course!” He said it was supposed to start in August of that very year, and he knew the doctor in charge.

He said, “I can talk to him about you and tell him that you’re interested in participating. I think you’re a perfect fit for the clinical trial.” I was so excited. I used to email the doctor often and ask him if he had heard anything yet. “Be patient,” he replied. “It should start in the fall. I’ll let you know.”

Unfortunately, time went by, and I didn’t hear anything about the clinical trial for a long time. I let it go. I thought, “Huh! He just said that to lift my spirits.”

[Margaret laughs as she changes the slide.] On the way back from my first appointment with Gary Abrams, I made a quick stop to eat at In-N-Out Burgers. [Margaret giggles.] This is my first time having these types of burgers. This is a picture of me with my sister at the In-N-Out that day.

[PANCHO RAMIREZ]: [*Pleased vocalization*]

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: Then, two years later, a message from that doctor, Gary Abrams of 2016, dropped into my inbox. It was somewhere in August of 2018, two whole years after. He said that the clinical trial was about to begin, and if I was still interested, that I should get in touch with the coordinator. I didn’t wait five minutes! I emailed her immediately.

She replied, I think within the same day, and set up a meeting to come to my place and do a screening on me. She came in with another person on August 31 of 2018. Then she asked me some questions and explained all about the clinical trial, and that it may require a surgery in the head to implant the so-called ECOG, I think. I just called it a microchip!

She continued, saying that the goal of the study was for the person to be able to operate a computer cursor, or mouse, and a robotic arm with his brain. Wow! I was blown away. Then she started talking about the other goal. She said, “Basically, you’re going to be doing two clinical trials in one.” The intention for the other part
of the trial was for a person unable to speak to be able to speak through a computer interface.

“What?! How could that be possible?” I asked her, and she explained it to me, but my team [laughs] will talk in detail about it.

[MARGARET SEATON]: And we did. [The neuroscientists laugh.]

On this screen there on the left, there’s a photo of one of the physicians on the trial, Dr. Adelyn Tu-Chan, and then on the right, there’s a picture of a brain.

And then quickly Pancho wanted to show the physicians who are in charge of the trial, who work closely with the team. So on the left, that’s Dr. Edward Chang, who we talked about earlier– the team, the group that we’re a part of. In the middle is Adelyn Tu-Chan, who we just spoke of. And then Karunesh Ganguly. They all work together with us, the large team, to run this trial with Pancho.

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: All right, so I had the surgery to implant the electrode in my brain on Monday, February 25th, 2019. It’s been more than three years since I had the surgery. A long time, isn’t it? It feels like it was done yesterday. Everything was very successful. I survived! [Laughter.] The surgeon was Dr. Edward Chang. And you can see here a photo of Pancho in the hospital with-- with his sister there.

Having the implant--

[MARGARET SEATON]: Oh, this is, sorry, one-- quickly, there’s a bunch of photos on the screen here, photos of various team members, and Pancho in the hospital, right after the surgery.

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: Having the implant has been sort of okay in terms of it being on my head. I do get light headaches occasionally. I feel like my neck is a little weak and my head weighs too much, but not so bad, not so uncomfortable. [Laughs.]

I can’t wet my head, also, so whenever I take a shower, it has to be done from the shoulders down. The nurses wash my head. It has to be done with a special treatment. Although at the beginning, the doctors did it for a while. They wanted to
make sure it was healing well. I have to keep my head bald. Well, I could’ve shaved just the spot where the connector is, but I think it’s better to cut all my hair, otherwise it gets pulled when connecting to the computer.

[MARGARET SEATON]: Very true.

[PANCHO RAMIREZ]: [Hums]

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: The first day [of] the actual study began in the month of March, 2019, as far as I can remember. As I mentioned earlier, I’m doing two clinical trials at once, robotics and speech, however, I would like to focus on speech today.

[MARGARET SEATON]: And then on the screen there is a photo of two researchers, so David is on the left, who spoke earlier, and then another researcher on the right, and then there’s Pancho, getting connected. [Margaret chuckles.]

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: My experience has been pretty amazing during all these years, although it has not been that great all the time. I do get tired sometimes, as well as very bored. Nevertheless, my research team-- I dare to call them my team!-- from UCSF is great, very nice, and fun. They make all the sessions go fast and smoothly.

They give me snacks, they buy me coffee, and take me to my favorite place, Dutch Bros. Coffee, to get it, if I want to. They make jokes, they do their best to keep me engaged and entertained.

Sometimes I feel like I’m back in school again. Especially when we were working on only data collection. For data collection, I have to say-- try to [say]-- the same word over and over again, for many days. I remember the very first time we started. It was about data collection every day. I thought, “OMG, are they trying to make me speak, or what?!” Days kept going on and on. Why did I sign up for this? I was starting to really regret that. Just like in school. [Laughter.]

[I wasn’t much of a good student who loves going to school. No, not at all. I was going to school because-- [Laughs.] I was going to school because I got in trouble if I didn’t! Anyway, the rewards were coming soon. Awesome ones.}
[MARGARET SEATON]: And on the screen here is Pancho in the recording session room as you saw earlier, and he's sitting and waiting to be connected.

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: So after the data collection, the team said, “Okay, Pancho, time for the truth. We’re going to do our first real-time decoding attempt.” I was sort of nervous. They said, “Just try your best. Don’t worry. If it doesn’t work, it’s not the end of the world. We’ll still collect the data, take it back, and make some adjustments and try again.”

Needless to say, it did work! I was very happy. I couldn’t believe it. I have a spontaneous laughter that comes out of nowhere for no reason, and I have a hard time controlling it--

[PANCHO RAMIREZ]: [Affirming vocalization, sounding a little wry]

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: --and putting myself together. On that day, I started laughing and laughing, and I thought it would never stop. I was telling myself, “Please calm down. You can do it. Erase that stupid laughter, you look like a dummy.” I kept saying that in my head over and over, and I did it. I took control of myself back, and continued the recording session. Yay. [Laughs]

Since that day, everything has been fantastic! I am excited about this clinical trial. Even when we were just collecting data. I know that great stuff is coming soon.

When I signed up for this clinical trial and I read the details about what it was about, I was very excited to get involved, but I didn’t pay much attention to the speech part. I did think it was great, but my focus was more on the robotics. I have always been hopeful of getting some body movement to be able to, in some way, at least, feed myself. Everything else would get much easier. Communicating will be a piece of cake. My idea was leaning towards the robotics.

[MARGARET SEATON]: Here’s a picture on the screen of Pancho with the robotic arm in the background, two photos.

Now I know much more about the clinical study, and I know both studies are very important, each one in its own way. I didn't realize the clinical trial could be beneficial, not just for me, but for individuals who, like me, can't speak and
communicate. I’m very happy to know that, and so my enthusiasm is greater every day I have a recording session. It’s a sad day when I’m not doing speech decoding.

My hope is that soon, the goals of the medical research would be achieved, and among many others, I would have the tools to fully communicate, have conversations with our loved ones, and a voice for our daily activities available to us. I love technology. I am successful because, thanks to God, I have the technology to bring myself forward.

Furthermore, I have a way to communicate, have conversations with my loved ones to get from point A to point Z, to collaborate with people from my organization. Without technology, none of this would be possible, I don’t think. Individuals like me could make it in life without technology, but if they do, it would be hard as heck.

And overall, Pancho's hopes for the trial is that this technology will become so good and widely available to individuals like myself unable to speak and communicate, to be easily accessible without having to be connected to any computer system, and that it’ll be affordable and at the reach of anybody’s pocket.

And thank you so much for listening to this presentation. [The neuroscientists applaud.]

[ERIKA PRADO]: Thank you all so very much. We’ll now move on to questions that were submitted by audience members in advance. So the first question that I will ask, is we received lots of questions about whether this technology might benefit people who are born with a speech-related disability as opposed to whether they acquired it like Pancho. So what does this research mean for people who were born with speech-related disabilities, for example, people who have never developed speech, as opposed to people like Pancho who lost speech later in life?

[DAVID MOSES]: Okay. Hi, this is David again. I can do my best to answer that question. There might be a-- I think that for us, there’s not a lot of research that currently exists to show what is possible in this type of approach for people who have not been able to speak from birth.

So, in some ways that’s kind of the bad news, but I think that there’s also good news. And the good news is that there are a lot of ways in which the brain adapts to
changes in the environment, and even things like brain computer interfaces. This topic is called neuroplasticity. It's a really fancy word that just means [that] the connections in the brain can change over time depending on what the needs of the user is, what the needs of the person with the brain [are].

And so, in that regard, they've shown that brain computer interfaces can actually facilitate this, in some ways, as you learn these skills. And so, what I'm envisioning, my assumption is that, further down the line, as this technology grows, it may be possible to teach someone to use a communication-based brain computer interface, similar to how someone would learn a new language.

So you would start with the basics. The person would try to say a sound like “Ah” or “Bee,” and then the brain computer interface would then learn these patterns, and then over time you could kind of build on this, similar, again, to learning a new language. And eventually, the dream is that you could then enable, kind of, fluent, natural speech by teaching someone to control a brand new... It's almost like controlling a new part or a new extension of themselves.

That's the way that-- I think is one potential avenue for this type of thing. But there's going to be a lot of research between here and there that, you know, but [with] the help of incredible people like Pancho and and others, I think we'll really be able to bring this further.

[ERIKA PRADO]: Thank you. There are also several people who asked about the logistics of accessing this technology, including Katie, a full-time AAC user, who writes, “Will this technology be available to others? Can we get in on any trials?”

[MARGARET SEATON]: Thank you so much for that question. It’s really an important question.

So for this clinical trial itself, as we’ve, I think, touched on throughout this presentation, this technology is very new, and we are working really hard-- well, Pancho's working really hard, with us, to get this technology to a place where we can motivate future clinical trials that could hopefully involve more people.

That's not saying that, you know, there's no room for other people to be involved in the trial. We're always looking for more participants. But that's just the way that this trial is set up right now: we have many specific guidelines for participation that
are set in place. If you specifically would like to chat a little bit more about this, or anybody, please feel free to reach out. We can give the emails, and I think those emails are listed in some of the CommunicationFIRST [materials].

I’d be more than happy to sit down with individuals and chat with them about their potential interests in our clinical trial, because it is an intricate set of eligibility criteria for the trial, this trial itself.

However, in general, really important for our trial, and for all trials that are focused on improving access for people with disabilities, any sort of input and feedback about the trial itself is invaluable, even if you should not be eligible at this time.

So anyways, thank you so much. I hope that answers your question and we will put our emails and my email specifically [in the chat]. I talk to people all the time about participating in this trial, so if anyone is interested, I would be more than happy to chat with you about that.

[ERIKA PRADO]: Okay, thank you.

[DAVID MOSES]: [Crosstalking] Erika?

[ERIKA PRADO]: Yes, go ahead.

[DAVID MOSES]: Sorry, I didn't mean to interrupt. I just want to add-- this is David again. One more thing about the other question that I think is really important that I forgot to mention, which is one of our main, I guess, principles that we always stick to, is that we know the information is in the brain. This is about the question “for people who are born without the ability to speak, could this type of technology help them?”

I just wanted to add that as long as someone knows what they want to say, and can try to say it, that information is in their brain somewhere. It’s just, how do we gain access to it? And so there are a lot of different-- you know, we have one type of implant as you saw in our presentation, but there are a variety of implants.

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1 The email Margaret mentions here can be found in the Q&A document for this webinar, which you can find with the rest of this webinar’s materials on our website.
And so it’s possible that even if our technology isn’t able to find this information, a different type of implant can, because again, it’s in the brain somewhere. We just have to learn how it’s represented, and how we can translate it into the intended messages from the user.

[ERIKA PRADO]: Thank you for adding that, David. I’ll move on to the next question. Sarah, a part-time AAC user, asks whether something like this will be possible for those with neurodegenerative diseases / atrophy from repetitive electrical trauma / repetitive brain injury.

[DAVID MOSES]: Yeah. So this is David again. I think that there’s, again, similar to the other question, there’s not a lot of research on this topic. Neurodegenerative disorders is something that I think we have a little more experience with than repetitive brain injury. But I’ll just go ahead and say this kind of general response: for what we think in our trial, what require-- there’s kind of two criteria that needs to be met for our current approach to work.

And that is that the speech motor cortex, so the part of the brain surface that allows you to control your face and control your vocal tract, that the neurons there are still relatively intact. So if there’s a lot of damage directly to that brain area, that would likely make it very difficult for our current approach to work.

And the second point is that the person understands language, comprehends language, and is able to attempt to speak. So we think that if those two conditions are met, our approach should work. That’s at least our hypothesis and what we continue to test in our work over the next-- right now and over the next few years.

But that’s not to say that if those two conditions aren’t met, then no technology will work for that person either. It’s just that’s what we have experience with, that’s what a lot of existing research has supported, is the idea that such an approach can be successful in these specific scenarios.

[ERIKA PRADO]: Thank you so much. This question is specifically for Pancho. Damon, a full-time AAC user asks, “Pancho, as a non-speaker who struggles with physically initiating typed communication. I would like to know, how easy is it for you to access this tech?”
Damon also asks in the Q&A today, he says, “I am autistic and mostly non-speaking. I am so interested in this communication technology because I absolutely can’t control my body in order to communicate my thoughts. I can’t say what my mind is thinking. I would love to see how this would work for someone like me. So [glad] that you are participating [in this clinical trial], Pancho! So helpful.”

[MARGARET SEATON]: So I’ll answer for Pancho. Pancho has typed out an answer for this, which I have access to. So thank you so much, Damon, for this question.

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: Unfortunately, right now we are in the early stages yet, and I don’t have any access to this technology unless I am plugged into the computer.

[MARGARET SEATON]: And this is something that the researchers-- that we do when we come in.

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: My hope is that it will become fully accessible by everyone who needs it without having to be connected by a cable in a soon period of time.

[ERIKA PRADO]: Thank you, Pancho. I’ll move on to the next question. Many questions were submitted asking about comparing it to other existing technologies. For example, Sarah, again, another part-time AAC user, asked, “In terms of fatigue, how does this method compare to infrared eye tracking?” Avery, a full-time AAC user, asked, “How is this technology similar to CART?” So, Computer Aided Real-time Transcription. “And text-to-speech?”

[MARGARET SEATON]: Yeah, those are great questions. Really, really interesting. So for-- I think the best way to answer this, at least from my perspective, would be, that the signals this technology uses are different from these other technologies that are mentioned. BCIs use directly recorded activity from the brain, which we talked a little bit about in our presentation, instead of using other attempted motor movements, like even eye movements or a finger movement or a cheek movement or a bite movement or something like that, BCI doesn’t require those movements.

So in theory, it would work if someone was unable to move any part of their body. And that’s the basis. So the way that the actual data is collected, the user intention is collected, is different. However, once that signal is collected from the brain, it
should be able to go to a variety of commands that would be able to be used [differently] for each user.

So if you wanted it to go to text, it could go to text. If you, hopefully, one day wanted to go to voice, it could go to voice, or if it wanted to control the face or go in a different language or something like that, then it could do all those things. So I’d say that, to answer your question, the really big difference is, how are we getting the data? How are we getting the user intention? And that’s where our technology is different.

And like Pancho has said, and us as well, we really are in early stages. So, this device isn’t something that can be used outside of research purposes at this time. But there is great potential for it to be able to get there.

[DAVID MOSES]: I think to add one more thing specifically about the eye trackers. We hope-- well, I’ll say two things.

One is, the reason why we’re so interested in speech as this, as our kind of control mode, is that speech for most people is the most natural and, you know, kind of efficient and fast mode of communication. So I know that not everyone is able to use speech to communicate, but if everyone can-- if we can re-enable people to use attempts to speak, to communicate, we think that that can be a really-- a way to control a communication interface that wouldn’t be too fatiguing.

And then just one other minor point is we hope to get to a point-- there’s no reason this technology needs to rely on attending to a screen, and have your head in this exact fixed position, [or] have this eye tracker, kind of monitor and make sure it’s tracking perfectly. And if you blink, it won’t mess it up.

You know, our technology shouldn’t-- it might have its own set of challenges, but it doesn’t have that issue where you have to attend closely to a screen and very carefully control this eye-gaze tracking system.

[JESSIE LIU]: Also, I guess there’s this part of a question that we didn’t answer before. I think this is part-- I think the second part of Damon’s question about whether people who are nonverbal [autistic people could use this technology], because that’s also a question that we get a lot. And I think Damon’s question is a
really great example, because just by virtue of him typing that out, you know, we know that the messages are in there.

And even though we’re focusing on speech motor cortex - so that’s the part of the brain that we sort of highlighted earlier - there are many other parts of the brain that control higher order aspects of language. And so those are things that just aren’t as well explored as speech motor. And I think this also goes hand in hand with the repeated traumatic brain injury, or neurodegenerative [disorders].

Even if one part is damaged, if it still is [the case] that other parts aren’t as damaged and they do have information, that can also be leveraged. So again, that’s all kind of like-- as long as you can think it, there’s theoretically a way to get to it, but a lot more research has to be done first before we can do that in a clinical trial like this.

[ERIKA PRADO]: Thank you. The next question is about Pancho, for Pancho, and your everyday life outside the lab, as well as your overall feelings about participating in the research. So Pancho, someone asked, “Pancho, how do you communicate in your daily life when you are not in the lab? What kind of supports do you need? And Pancho, how do you feel about participating in this research?”

[MARGARET SEATON]: Okay. Hi everyone. Margaret, I’m going to answer for Pancho. Pancho has typed out his response here, so I’ll read it. So in answer to how Pancho communicates in daily life, when you’re not in the lab, and what kind of supports do you need, Pancho has written:

[MARGARET SEATON, READING PANCHO’S PREPARED REMARKS]: I use a head mouse to operate a desktop computer and communicate with everyone - write emails, watch movies, type messages, and do pretty much everything on a computer. This device is so awesome, an incredible thing. It’s called the Quha Zono. It comes in two pieces. One is the receiver, like a USB device. It connects to the computer and automatically pairs both devices. The second one, the mouse, could be on your glasses or in a holder that goes over the head like a headband.

The UCSF researchers from San Francisco gave me a laser pointer and a letter board so I can have them in my bag all the time, and use them on the go if I need to. I can’t do anything for myself, unfortunately. I have to have help with everything.
[MARGARET SEATON]: And then in answer to the question about how Pancho feels about participating in this research:

[MARGARET SEATON, READING PANCHO'S PREPARED REMARKS]: I am very happy to be involved in this amazing clinical trial. I love doing my sessions with my team, especially since I know the benefits will not be for myself only, but for many people who, like me, cannot speak or communicate.

[ERIKA PRADO]: Thank you, Pancho. Um, someone else, someone else also asked if your expectations of the trials have been realized.

[MARGARET SEATON]: Okay. Yeah. So Pancho has written:

[MARGARET SEATON, READING PANCHO'S PREPARED REMARKS]: Not yet, but I’m hopeful they will soon.

[ERIKA PRADO]: Thank you. Another question is: How easy is the interface to position / set up by carers?

[The neuroscientists briefly talk amongst themselves.]

[MAX DOUGHERTY]: Oh, yeah, sure. So, in terms of training somebody to be able to connect, I think what we’ve found is that it currently still requires some sterile procedure for that to work well, but it is fairly simple to train new people who have some familiarity with staying sterile to connect.

So feasibly when we can kind of have this system more readily deployed, it would not take an expert to be able to connect Pancho to the communication device, both for collecting data to train the system, but also for him to actively do decoding. And it’s very feasible for somebody to do within their own home.

[JESSIE LIU]: Yeah, the one difficulty is we use a fairly large computer, and so that is maybe not-- [laughter] that’s not so easy to teach people how to use. It’s definitely not impossible.

But there’s also-- there’s work from other groups that are trying to make this really big rig and computer that we use, make that much more portable. So there’s a group from the University of Pittsburgh that actually put it all onto a tablet. It was
kind of a chunky tablet, but the person was able to, you know, carry it around, and, like, they could freely move about their house while using the system. So that’s also another line of really great work that will definitely, you know, benefit the ease of use of this.

[MARGARET SEATON]: Yeah. And one more thing to add. I do think that, just to be clear, when Pancho is using the device, as Max was saying, the research team has to be there. So this is not something that Pancho can use, as he was saying, when he’s in his room by himself or with his caregivers or with other nurses. We have to be there.

So that’s something that has to do with what Max was talking about with the [sterile] connection and everything. So just to be very clear about that.

[DAVID MOSES]: But to add - yeah - I’ll add also that there’s a lot of work not just by our group, but by many groups now, including some companies, to get this technology to be fully implanted, and wireless.

And so what that would mean-- so right now, as you saw in the slides we shared, there’s this kind of metal tube, if you want to imagine it, that’s allowing the brain implant to connect through, and then we connect that to our computer. But it seems very [likely], you know, in the near future that there will be hardware - brain implant hardware - that will be fully wireless, that can achieve similar types of data acquisition that we’re currently doing.

So this will be something that’s implanted and it will send the data out and connect to an external device. And the main advantage-- well, one of the main advantages is that there’ll be no risk of infection. You wouldn’t need someone to connect or to maintain, you know, a nice clean area around this metal tube, because everything will be implanted and just-- it’ll be ready to go. You won’t need to deal with any cables or anything like that.

And it could connect to a tablet or a computer. You know, that’s the goal not just for our group, but for many groups. Yeah.

[ERIKA PRADO]: That’s great. Thank you. There was a quick clarification question in the Q&A chat. If you can please spell the name of the head mouse that was just discussed by Pancho?
[MARGARET SEATON]: Yes.

[DAVID MOSES]: You remember where it was?

[MARGARET SEATON]: Yeah. It is spelled Q U H A, space, Z as in… Zebra?

[MAX DOUGHERTY]: [Crosstalking] Zoo. [Laughter from the neuroscientists.]

[MARGARET SEATON]: O--

[MAX DOUGHERTY]: O N O.

[DAVID MOSES]: That’s November...

[MARGARET SEATON]: Maybe we can type it in the chat as well.

[DAVID MOSES]: Yeah.

[MARGARET SEATON]: [Raising her voice] We can type in the chat too. Yeah.

[ERIKA PRADO]: Yeah, perfect. Thank you.

[DAVID MOSES]: Can I also add-- I think we may have also missed this question, or either that or I-- I think it’s, it came up a few times in the Q&A, is that there’s also a clinical trial that’s separate from what we do.

It does not use brain implants, but it focuses on research with individuals that have Autism Spectrum Disorder and many of whom are nonverbal. And so I can place a link in the chat to the website for that trial at UCSF for you to learn more. Because, you know, the brief summary for us is that we don’t have a lot of experience, and there’s kind of a lack of research [on] if our approach could work for individuals with nonverbal autism.

So, I think this trial will be a great resource for those who are interested in learning more about what kind of research is being done for that.
[ERIKA PRADO]: Yeah. There were some questions for-- about the trials with nonspeaking autistic individuals. Yes. Thank you.

There was a question about-- So how does BCI meet Pancho's bilingual needs yet? Do they? Or is this still in progress?

[DAVID MOSES]: Well, the short answer is that it’s still in progress, so… A slightly longer answer is that the signals that we think we’re tapping into, when we work with Pancho and when he tries to speak, we think that these are not really language-specific. And by that I mean they should be able to work to enable communication in many languages, not just English.

And so we’re currently working with Pancho to see how far we can, you know, to see what we can learn from a type of bilingual approach. Because Pancho is a native Spanish speaker, but also learned English.

And so, it’s kind of, you know-- if he wasn't already an amazing team member and collaborator, now he has this extra thing to help us answer this, a really important research question. So I would just say that for now-- oh yeah, and he's learning French. That’s right.

But just stay tuned for that. We should have some findings soon, I hope.

[ERIKA PRADO]: It’s amazing. Thank you.

We also had a question here in the Q&A. It’s Bob Williams. It says, “You have mentioned the lack of research as a major barrier to addressing many of the challenges people have raised. Can you speak to what needs to happen to close some of those gaps?”

[JESSIE LIU]: Yeah. I think-- This is Jessie, by the way. This is a really excellent question, and. So a lot of our research, also, is of the specific type of neural signal, that these are the ECOG signals. Now, ECOG is an invasive method. That means you have to actually get, you know, past the skull. And that requires surgery, but the signal [is] much higher quality. You can get much better resolution, basically.
But the downside is that to learn about those signals, and to learn about what kinds of patterns you can leverage, you do need that data to start with. And so that’s what we’ve gotten with the epilepsy patients.

And those patients only have those ECOG grids in temporarily in the hospital for other reasons. We’re not just having them have surgery just for us to get some data and learn about it, and for them to go home and, you know, not do anything else.

So one thing is [that] improving non-invasive neural technologies will be really huge in expanding the amount of research that you can do, because you would be able to do a lot of work with people who are not going to get brain surgery, but still learn about those signals. And there are a lot of people trying to improve that just for that reason, and to be able to bring neural data to a lot-- a much wider audience.

And so that’s one effort that I think is really important for getting that ground truth data, which could then motivate doing more invasive approaches. I don’t know if anyone else has other thoughts about that.

[DAVID MOSES]: No, I think-- One other thing I would like to add, just back to the point of Autism Spectrum Disorder individuals, is... I think a lot of it was also just kind of [a] misconception of the-- in some ways a misdiagnosis of the disease.

Like, for example, I think-- well, I hope that none of you have ever had to go through this, but I know it’s likely that some of you have, where just because you might not be able to communicate as rapidly as someone else, it doesn’t mean that you don’t know as much or that, you know, you don’t have an understanding or comprehension level similar to others.

And I think these things have also slowed down this type of research, where if someone's unable to communicate, it may not be clear to society at large, maybe, that these people still-- they understand what they want to say, and they know what they want to say, and they can potentially even try to say it, but it just doesn’t come out.

And so, for us to really understand how wide-reaching our type of approaches can be, I think part of it is basically [that] this type of conception needs to go away, so that we can truly get a deeper understanding of the signals-- the types of signals
that we can get. What is there and what’s not there? And how we can make this technology work for many populations.

[ERIKA PRADO]: All right. Thank you so much, everyone. Let’s all hear it for our panelists. We’ve just run out of time. Thank you so much for participating. We all really appreciate you taking the time to be with us today and we learned so, so much.

Today’s webinar was recorded and so once the transcripts have been produced and corrected, and we can produce accurate captions, a video recording with open captions in both Spanish and English will be available on our website.

We will send out an announcement about it being available through our newsletter. So be sure to sign up at communicationfirst.org if you haven’t done so already. And I’ll now pass it over to Tauna. Thank you.

[TAUNA SZYMANSKI]: Thank you so much, Erika, and thanks to everyone for attending today’s event and for submitting such great questions. Sorry if we didn’t get to your question. We did try to answer as many as we could.

I also want to thank our amazing presenters, so much. We are so excited to follow this incredible work as it continues, and we wish you the best of luck.

And finally, thanks to our simultaneous ASL and Spanish interpreters and live captioner for helping to make this event accessible to a larger number of people in our community.

If you appreciated this webinar and its accessibility features, if you happen to be in a position to do so, we’d welcome your financial support to ensure we can continue to organize events like this and to make them as successful as possible. Please visit communicationfirst.org/donate to make a tax-deductible donation.

And you can also support us by ordering and proudly wearing one of our exclusive T-shirts, with catchy communication rights slogans on them. These are only available through this Friday, October 21st, so you should place your order today.

I’m going to share my screen, so you can just have a quick visual image of them.
So that’s just a sampling. They’re available in many different colors and sizes. And so those, again, are only available till Friday. One of them says, *Speech does not make someone more human*, and that was a quote from Jordyn Zimmerman. One says, *Communication is a basic human need, a basic human right. And more than that, it is a basic human power.* That’s a quote from Bob Williams. And then the third just has our tagline: *Because communication is a human right.*

Okay, so, with that, I want to thank you all once again for attending, and we look forward to seeing you at a future event. Thank you so much.

*[PANCHO RAMIREZ]:* Mm-hmm.

*[DAVID MOSES]:* Thank you.

*[MARGARET SEATON]:* Thank you!