Knispel: Welcome to the University of Rochester Quadcast. I’m your host Sandra Knispel. Joining me today is Dr. Krystel Huxlin, she is the James V. Aquavella Professor and Director of Research at the Flaum Eye Institute at the University of Rochester. Welcome Dr. Huxlin.

Huxlin: Thank you.

Knispel: Now Professor Huxlin an expert in repairing adult visual systems and she does this via vision therapy. For whom does this kind of therapy work? Whom do you address? What kind of patient are you looking for?

Huxlin: So right now the therapy is customized and really made to work for people who suffered vision loss as a result of a stroke, which damaged part of the visual processing centers of the brain and stroke is the major cause of this. In some cases traumatic brain injury or even tumors can end up with the same result.

Knispel: Now vision training, the kind that you researching, can actually recover vision. Would you explain how this actually works?

Huxlin: Well, that’s a bit of a mystery still so we’re still trying to understand how the brain achieves this recovery, but it seems to us that part of what happens when you have a stroke is that you have a region of the brain that dies and the cells there, the neurons, the glial cells, the supporting cells—they all die and if this area processed vision normally, then you are going to lose your conscious sight over a portion of your visual field. And traditionally we thought you could not do anything about this, but one of the things we have discovered is that strokes rarely destroy the entire parts of the brain, all of the parts of the brain that process visual information. There’s often a lot of them still intact. They’re just not used to processing that information without the part that has been destroyed. So, essentially what we think is happening is that the visual training that we do in our patients forces these areas, these visual processing centers of the brain that are left over, to efficiently process visual information sufficiently well enough that it actually reaches consciousness once more.

02:18 Knispel: What would one have to do in order to retrain once vision after a stroke? What kind of training is that?

02:24 Huxlin: First you have to figure out what ability has been lost. What visual ability has been lost and then that is exactly what you train, but you have to train it in the blind field specifically. So, our approach is to present a visual stimulus inside the blind field and to ask the person to tell us something about that visual stimulus—whether it’s moving right, whether it’s moving left, or if it’s oriented horizontally, or vertically—so some attribute of the visual information that’s in the blind field and then we give them feedback on every trial and we make them do this thousands of times over periods of months usually.

03:06 Knispel: So, say I am a stroke victim, first of all is this vision therapy something that I have to do immediately, or do I have months, years to get to it?

03:17 Huxlin: Well, our most recent research results suggest the sooner you start the therapy after stroke the faster the recovery you might be able to get and the more recovery you might be able to attain. This is something that’s not exactly novel. It’s been shown over and over again with people who suffer from motor strokes for instance. The same principles really apply with vision. However, we’ve also worked with people who had strokes years prior and even in those folks we were still able to actually get visual improvement. It’s as if there’s part of the brain that is sitting there, capable of processing visual information but it doesn’t do that on its own until you force it to do it.

04:02 Knispel: So, it’s kind of getting the backup started.

04:05 Huxlin: Pretty much. Yes.

04:07 Knispel: In order to relearn to see, how many hours of training a day and for how long would I have to do this?

04:14 Huxlin: So we ask our patients to train for one hour a day, every day if possible. Again it depends on how long ago the stroke was. If it was two weeks ago, it tends to take maybe a week or two of daily training to achieve a certain level of recovery, whereas the same level of recovery requires months of training for somebody who starts six months after a stroke or more.

04:39 Knispel: So, time really is essential. What’s your success rate?

04:42 Huxlin: So, if people do exactly what we tell them and they don’t cheat, the success rate has been in our hands a hundred percent.

04:52 Knispel: Tell me how one would cheat?

04:53 Huxlin: So, the main problem with cheating that we have is people moving their eyes and trying to look at the stimulus directly with their eyes, rather than letting the stimulus stay in the blind field. It’s unfortunately for this particular purpose, it’s an instinctive reaction in us humans that when we see something in our visual periphery we want to look at it directly and it’s exactly this instinctive reaction we have to fight when we’re trying to train the blind field.

05:23 Knispel: Could this therapy also be used with people who have damage to their eyes, who’ve got something in their eyes, or lost part of their vision because something damaged the eye directly?

05:34 Huxlin: You can use this therapy but the result will be different. When you have damage to the eyes you lose the input, the visual input to the entire visual system and because of that, that may not actually work to try and retrain them and recover vision. However, you can use this form of training, not to recover vision necessarily but to teach people to better use whatever vision they have left, so I think there’s many more uses of the kind of training we’ve developed than just restoring vision after stroke.

06:10 Knispel: Now you here at the Flaum Institute, you’re the only lab in the US that does this kind of visual research. What does that mean for you when you do trials?

06:20 Huxlin: We feel like the lone voice in the wilderness. It is my hope, honestly, that in the next few decades that there will be more scientists who turn their attention to this problem and ways of resolving it, but for now it means that we are essentially the only ones who are able to really launch a clinical trial for instance because we’re the only ones that have the expertise to do it correctly.

06:44 Knispel: And you are, that’s the exciting news, just about to launch that clinical trial.

06:49 Huxlin: Oh, yes. So we’ve been working at this for a very long time and now we’re finally actually making inroads towards deploying this approach, this visual retraining approach as a clinical treatment. So, the first step is for us to do a clinical trial of the therapy and then, hopefully, to get FDA approval for this technology, and then to deploy it in the clinic where, honestly, it should be administered just as automatically to patients with strokes as physical therapy is for patients with motor strokes.

07:20 Knispel: And who’s funding the clinical trials and who’s participating in them?

07:24 Huxlin: So currently there are three funding sources for this very small clinical trial. One is the University of Rochester through CEIS and along with NYSTAR, so this is New York state funding. We also have partial funding from the Data Science Institute as we are hoping to collect a lot of data, population data, within this clinical trial, and finally the trial is sponsored by Envision LLC, which is a startup company that has as its major goal deploying this technology commercially.

07:58 Knispel: So if somebody’s listening to this who knows somebody who’s just experienced a stroke or has himself, herself, suffered a stroke, what are the chances for this person to actually get the visual therapy right now that they need?

08:09 Huxlin: Very unlikely. Bcause we are the only centers who can get, who can give out or perform this visual training, and we can only currently perform it under the auspices of our research so this is NIH funded research that our lab has been doing for the last ten years or so, so we can enroll patients into our research studies and that’s it for now. When we launch the clinical trial people might have the opportunity to also enroll in a clinical trial but that is essentially it at this point and that is one of the big problems in this field for this patient population. So, there are very few resources that most people have access to in their hometowns in terms of visual rehabilitation. I should say that right now the associations like the Association for the Blind and Visually Impaired here in Rochester are one of the few places where people can undergo some form of visual training, visual rehabilitation. It doesn’t involve our training therapy yet, but hopefully down the road after we get FDA approval they will be able to and places like the ABVI will be able to deploy our therapy alongside their restitution, and substitution, and compensation therapies.

09:28 Knispel: And I guess what is so frustrating, what must be most frustrating for you— here you are, you have essentially a silver bullet when you say a hundred percent success rate. And it’s not complicated machinery that the patients need, so everything is there. You’re just missing the channel to get it to the patient.

09:45 Huxlin: Yes, that’s right. So, people can do this training and our patients, even the ones that are enrolled in our research studies, yes we do, we do need them to come to Rochester for us to perform all of the tests necessary for the research, but then we send them home and they train at home for however many months they need to train with just their own home computer. We give them the software, the training software that they install on their computer and a chin rest. So, that is essentially, that’s the extent of the technology involved. It’s not, that’s not the difficult thing. The difficult thing is to have the correct instruction on how to do the training correctly and that’s key to success ultimately.

10:28 Knispel: So, realistically how long do you think it will take for this therapy to be broadly, widely available?

10:34 Huxlin: I’m hoping no more than a couple of years and that’s assuming that the clinical trial and FDA approval goes smoothly but that is the hope. I mean, we really have no time to waste, you know. There’s a saying in the neurology community that time is brain, and I would say that in this case—time is vision.

10:58 Knispel: Do those visual gains—basically when you recover your vision, these gains, do they stay with you or do you have to keep retraining sort of like muscle tissue if you don’t go to the gym you lose it?

11:09 Huxlin: Well that’s the beauty of the visual system. So, we’ve shown that our form of training can actually recover parts of the visual field that had previously gone blind. Once people are able to reengage part of their visual field in their everyday life, they pay attention to those regions of the visual field and they use them—then they tend to perform—that acts like exercise on its own. And so, they can reinforce just by looking around themselves in everyday life. They can reinforce the training that we gave them, so, no, we have not found that you need to continue this forever, the therapy itself. I think that once you get to a certain point and you’ve recovered enough to be functional, then you tend to keep that recovery as long as you use your vision in your everyday life.

12:00 Knispel: In your presentation you mentioned barriers within the medical community and I’m wondering if you can briefly explain what the problem is.

12:07 Huxlin: The problem is that this approach to try and use visual training to recover vision after a stroke has been used and proposed a long time ago by a different company that ended up going commercial very quickly. And this company, I don’t think, used the best, most rigorous scientific approaches to do this work. Unfortunately, they were discredited a number of years ago and as a result of that the medical profession kind of took many steps back and a lot of people within the profession felt that, well, this was evidence you could not retrain vision after a stroke. So, really part of our struggle has been to fight against that assumption and to show that if you do training correctly and you use rigorous scientific approaches to measure the outcome to rule out potential biases on confounds that you can still attain visual recovery. And so, convincing the medical scientific community of these new realities for the field is one of the difficulties that we are facing today.

13:22 Knispel: So, it might also take quite a bit of advocating on the part of the actual stroke victim. What is it that you would say to any primary care physician who’s listening?

13:32 Huxlin: That these patients of theirs have hope and, in fact, the more active they can be and the more advocating they can do on their own behalf, the better we are all going to be. At the end of the day, the patients should be demanding treatment, and should some of them do and that’s how they find us essentially, but I think that they should also be demanding this higher level of rigor from their own physicians.

14:01 Knispel: And always keep in mind—time is brain.

14:03 Huxlin: And vision!

Knispel: Thank you so much Dr. Krystel Huxlin for the interview.

Huxlin: Thank you very much.

Knispel: Dr. Huxlin—again— is the James V. Aquavella Professor and Director of Research at the Flaum Eye Institute at the University of Rochester. For the University of Rochester Quadcast I’m your host Sandra Knispel, thanks for joining us.