September 24, 2024

Chair Gelser-Blouin and Members of the Senate Human Services Committee:

My name is Kathryn Nichols. I am the mother of a 31-year old son who sustained a severe brain injury in a climbing accident 7 years ago. I testified in February of 2023 when SB 420 was first introduced in your committee.

David Kracke, the *State's Brain Injury Policy Coordinator*, my son and I advocated through the 2023 session for passage of this important bill. Both Daves send their greetings and gratitude for your role in passing SB420.

Over the last year, we have all been watching and waiting patiently to see how the new office will take shape. Those with brain injuries are not the most patient lot, but we are excited that a new Program Director has finally been hired. I met her earlier this month and am impressed by the passion and skills she brings to the job. We also recognize that she will have her hands full to create the new program, recruit talented staff, identify the broad and complex resources around the state that the office can refer those with brain injuries to, market the new program to referring entities, and build new partnerships with other state, local and non-profit agencies that serve this community. It will also be critical to set up robust data systems that collect the requisite information to report back to the legislature on gaps in brain injury programs and services. Since this is a new program, we are still in a learning mode about whether the Brain Injury Office is right-sized and whether we have gauged appropriately the demand and scope of services needed. All of us who came together on passage of SB 420, will be standing by to support and assist the new

Director and staff as the new program is rolled out. We are very excited to see how many survivors and their families can be helped going forward.

Brain injury advocates around the country are watching to see what will come next in Oregon with the synergy and support we created with SB 420. The *Center on Brain Injury Research and Training* at the U of O hosted a national conference on Brain Injury in Eugene earlier this month. A small team from Oregon attended an excellent national conference on TBI Rehabilitation in Las Vegas this spring. We were all very impressed by the body of new transformational science in the pipeline to really improve clinical practices after brain injury. We plan to take a larger team of advocates and clinicians to an International Conference in Montreal next spring to learn more together about new science and best practices in brain injury rehabilitation.

Now that creation of Oregon's new Brain Injury Office is underway, I am shifting attention to building support to build a World Class Neuro Rehabilitation Center here so those with complex brain injuries like our son's do not have to go out-of-state. The upcoming merger between OHSU and Legacy creates new opportunities to re-imagine our inpatient rehabilitation facilities. This summer, Representatives Reynolds and Nelson took a team of Oregon's DNC delegates to see first-hand what Transformational Rehabilitation looks like at the *Shirley Ryan Ability Lab* in Chicago. They were VERY impressed by what they saw. Shirley Ryan is the largest and highest rated program in the country. It is currently breaking ground on a new facility in Detroit, and are eager to assist in Oregon when the time is right.

I thank you for your time.

Caring Bridge Post by Jenny Brooks, Mother of Ava Brooks
Residents of South Eugene, Oregon

- **January of 2024 Ava Suffered an AVM-based Brain Bleed as a Freshman at the U of Oregon**
- **Airlifted to Craig Hospital in Colorado for Inpatient Rehabilitation**
- **Currently at QLI in Nebraska for Outpatient Rehabilitation**

Sep 19, 2024 (9 months post injury)
The Two As

In one of my first posts after Ava arrived at Craig Hospital in Denver, I explained what the doctor showed us in her imaging and the damage in her brain from the brain bleed and stroke. The major damage was to the basal ganglia, which is primarily the speech center.

When you are in the middle of crisis, and you have lots of people trying to tell you the potential your daughter has for recovery – all in cryptic, non-predictive language – you do your best to distill it into language you can understand and communicate. At Craig, after her first couple of weeks there, I remember being told their assessment was basically that she is likely to recover physically, but she may never speak again. That's what I took away from a discussion and when I repeated it back at a meeting with her team, no one argued.

For me, that was the measuring stick and the challenge.

When she got to Craig she couldn't even swallow. She had a suction system so we could suck her spit out of the way for her, and she was eating through a continuous feeding tube in her stomach. She was able to give us some thumbs up or down here and there, but it wasn't always accurate.

Before we could worry about speaking, the work in speech therapy started with teaching her how to swallow and use her tongue. That took the whole of the time she was at Craig. When she left at the end of May she had just started eating food in any real way.

Anyway, fast forward seven months from her arrival at Craig and almost four months at QLI, and she's definitely proving the physical recovery prediction to be true. All this week we've just increased her walking with a cane and moderate assistance. She isn't walking everywhere yet, but it's increasing every day. Her pride in herself is on full display, which is wonderful because it means she's seeing the fruits of HER labor. Hopefully that inspires her to keep working.

Now, the second part of all of this is her speech.

A couple of weeks ago she had a psychological evaluation (my words - can't remember its official title). They shared the results with us last week. The positive is all signs point to Ava's strong cognitive abilities. Basically, she's all there, and she's still herself.

I knew that :) But it's helpful to have it confirmed by experts.

But the test confirmed what we've all been observing when it comes to speech, processing information and reading/writing.

Please note this is a very layman's explanation and has not been endorsed by her specialists!!!!

The best way to explain it, I think, is to provide the definitions of what's happening in her brain. She has:

- **Apraxia of speech,** also called verbal apraxia, a speech sound disorder affecting an individual's ability to translate conscious speech plans into motor plans, which results in limited and difficult speech ability. By the definition of apraxia, AOS affects *volitional movement pattern*.
- **Aphasia** is a disorder that affects how you communicate. It can impact your speech, as well as the way you write and understand both spoken and written language. (Thanks, Wikipedia, for the definitions.)

Oftentimes Ava will go to say something, and it comes out in a simple phrase she has at the ready, like "I love you." And she'll hear it come out and be like, "Oh." Because that's not what she was trying to say. And when you're trying to teach her a new word to say, she can't just repeat it. She has to watch your mouth and there are lots of letters that are hard for her to form and understand.

Because the loop in her brain has gaps in the process/steps that are required to speak. She has trouble initiating - meaning speaking without being cued. And she has trouble processing the taking in and repeating new words and information. Again, just gaps in the processing loop.

But the more she practices a word or short phrase, the more it becomes common for her to be able to say. Like the bridge is being rebuilt slowly but surely.

You can see her brain struggling to process explanations and questions, which is the apraxia. But once you give her time, she gets it. It's hard to explain without being with her all the time, but there is often a delay in processing. But once it's processed, she's on it. That is usually with more complex questions, thoughts and dialog. But she's on point for what's going on around her and if you give her a beat to let the loop run in her head.

Right now our mission is to get her to stop using thumbs up and down and to speak "Yes" and "No." This week has been the trial of that approach, and it's mostly working.

Will she be able to fully recover her speech and her ability to read? No one can say with certainty, but I say yes. She's 19 years old, incredibly smart and driven. Neuroplasticity is a real thing - her brain is completely rebuilding what she's lost, and we're watching it happen. And she's had the most intensive therapy available in the best settings. And she's Ava.

Will it be soon? I think it's going to be a while - likely a couple of years. And based on her cognitive testing/psych eval, all signs point to her potential. It's not certainty but the potential is there.

It's just one more step in understanding her losses and all the work she has to do to rebuild herself and her future.

Source: https://www.caringbridge.org/site/91bd8bd8-a2a7-3c23-83e0-c33ba773e0be/post/e18c9446-dc6b-4e0e-bf3d-47d18e9593cb?utm_source=amazonses&utm_medium=email&utm_campaign=$das_followers