

The Accessible Stall Podcast

Episode 41: Awareness, Campaigns and Colors

Emily: Hi, I'm Emily Ladau

Kyle: And I'm Kyle Khachadurian

Emily: And you're listening to another episode of *The Accessible Stall*

Kyle: Hey. Emily

Emily: Hey, Kyle

Kyle: What are we gonna talk about today?

Emily: Oh, you threw me off my game. You usually just say, "What are we gonna talk about today, Emily?"

Kyle: I felt like changing it up, it's been awhile

Emily: Wow, okay so now that I just need to regroup my thoughts entirely... No. So today we're gonna talk about awareness and do we need it, and why

Kyle: Oh boy... uhh what is awareness? I'm not aware of what awareness is. Make me aware?

Emily: Would you like me to increase your awareness?

Kyle: I would.

(Emily laughs)

Emily: Um...I think awareness is a super loaded term. I don't actually know what it means. You know what? I don't have an answer to that question. And by the end of this episode I would like to figure out exactly how to define awareness. Because technically, awareness simply means that you have a consciousness of something. I'm not really sure what having a consciousness of a disability accomplishes.

Kyle: Yeah, I mean I don't know. This all stemmed from the fact that it was World CP Day 2017 recently. So for all the people out there who listen to us that have CP, happy day!

(Emily chuckles)

Kyle: And you know it's just one of those things that we all love to celebrate for a day, we all like to be like, "Oh, Happy CP Day!" But I find it ultimately very hollow. Because I feel like...I'm actually very conflicted with CP in particular, because I agree with you that most awareness is like vapid, cause like who needs to be made more aware of like, Breast Cancer for example? Susan G. Komen's a horrible charity, they do it every year, and every year people who wear pink and that do nothing else and they think they're helping. But with CP Day it's like, it's so common and no one even knows how common it is, or what it is and what it does to a person. So the awareness is necessary. But I think more than personal awareness you need medical awareness. Like, doctors don't know what to do with us. Average Joes knowing what CP is, is nice I guess but it's really not even half the battle, especially when you become an adult.

Emily: I have like, a hundred things I want to say to that right now. Because you brought up so many things I want to talk about.

Kyle: Yeah I'm so sorry I just unloaded, and I'm not even done! Go on..

Emily: No it's great, no it's great.

Kyle: No please, no please, one by one let's go!

Emily: So um, wait let me just say all the things I want to address, and then we'll try to make sure we double back.

Kyle: Mhmm

Emily: So, first of all I have a question about the nature of it being celebratory. Second of all, I wanna talk about the whole, "Wear Pink for Breast Cancer" and why I feel like that's so frustrating. And the third thing is you talked about medical awareness.

Kyle: Mhmm

Emily: So there is a lot to...

Kyle: Unpack here?

Emily: Yeah!

Kyle: I feel like anyone listening is not going to understand why we enjoy that phrase so much. Because up until like the last three episodes, Emily has said that in like every episode. So now it's a big joke.

Emily: I mean, it feels just the most accurate description of what we're trying to do. We're like, pulling these metaphorical things out of a box, examining them. I'm like making the motion of pulling things out of a box right now. *(laughs)*

Kyle: Me, too yeah.

Emily: So can we remember that list of three thing long enough to touch on all of them?

Kyle: Probably not, but go on.

Emily: So the first thing...

Kyle: You said celebratory was first.

Emily: Yes, exactly. So the reason I wanted to talk about that is because that is a really interesting like, the fact that...and I noticed this too because I am friends with a ton of people with Cerebral Palsy on Facebook. And everything is like, "Happy World CP Day!" And celebratory is not a thing that I associate with most awareness days. And so, is that unique unto certain disabilities? And if so, why is this whole thing seen as celebratory for you? Are you celebrating your existence? Are you celebrating making people aware of your existence? What is it?

Kyle: The answer to your question is "yes." Honestly, I'm not even being funny. The answer to your question is, it's both. I mean, I find it kinda silly, but it's lighthearted enough where it's not doing anything harmful really. So, I just see it as like a day where you make people aware about CP. People don't know about CP. Disability people know about CP. Every in the disability community knows someone with CP, it's a very common disability in the Disability community. That's because it's a very common disability in the world. It's three in a thousand, and no one knows about it. Nobody knows about it! I know you know about that, Emily. You know the feeling about what it's like to bring up Larsen's Syndrome, but at least you have the benefit of that being rare. CP is common. CP is *very* common. And so, you know it's like, "Oh we're

here!” You know, “Happy Day!” but you know, for me it’s mostly harmless. So, it’s all in good fun.

Emily: I think the word “celebratory” struck me in particular because, first of all, a lot of people would obviously perceive having a disability as something to pity, and here we all are being like, “Happy CP Day!” You know, so that’s the first thing.

Kyle: Yeah, for sure.

Emily: And then I guess the other thing is a lot of other awareness days are so focused on negative things that you just don’t want to celebrate like Breast Cancer awareness. Um, you know...And the other thing too is like, this month, October, is National Disability Employment Awareness Month. And I understand the intent behind it, but my question is, so we’re asking employers to be more aware of hiring disabled people, right? But it’s all like “We’re celebrating National Disability Employment Awareness Month!” Okay, but what about the other eleven months out of the year?

Kyle: Well, I mean, I don’t know. I hear you, but I think that the purpose of that is to call attention to a specific issue in a certain time so you can sort of focus the world’s attention on it for awhile. And I get that. But, at the same time it shouldn’t go out the window at the end of Oct...at the end of Sept..at the end of October, excuse me. You know it’s like, “Okay we did it! Halloween’s over okay we can move onto the next thing”

(Emily laughs)

Kyle: And that’s what we do, and it’s a shame, it’s sort of like, “What’s the cause now?”

Emily: Yeah and believe me, I am not against raising awareness for the need to have more inclusive workplaces. In no way am I saying that it’s a bad thing but I think that having awareness days and awareness months after a awhile...I just wonder if they start to feel a little too arbitrary and redundant? And are they accomplishing anything, or is it just like a “friendly reminder” *nudge, nudge* pay attention, change your Facebook profile photo, etc.

Kyle: I mean, *(sighs)* I don’t know. I think when it comes to disability it’s a little different than when it comes to like disease. Because I don’t find World CP Day particularly important but I can understand how somebody with CP totally would. The part that I find important about it is...there must be more awareness. It’s shockingly common, like that’s the thing. And you know, I want it to get to a point where I’m sick of seeing green everywhere in the same way I’m sick of

seeing pink everywhere. That's where I want that to be. It'll never be there, like I don't think, but...

Emily: I mean you actually pointed to my next point about you know,

Kyle: I'm trying to make you remember!

Emily: About the whole branding thing

Kyle: Just doing what ya asked!

Emily: Much appreciated. But at the same time I have a couple more points I want to talk about related to our first point. I guess just in general something that I noticed is it's for a day everyone is like, "Hey so and so awareness day, be aware of it blah blah blah...Okay moving on!" But how can we really take advantage of stuff like that and turn it into something educational? I have a friend who has CP, um I actually met her at a concert several years ago and we've since stayed in touch and we've actually gone to concerts together. That's neither here nor there, just a fun fact...all disabled people like to hang out with each other. And she takes the whole idea of CP Awareness and turns it into like a month long educational series of social media posts.

Kyle: Do I know this person?

Emily: I don't think so actually but she's really great!

Kyle: I'd like to

Emily: Yeah, I'll introduce you.

Kyle: Cause the thing...you raise a really good point. Because the whole point of awareness campaigns is to make you more aware. But like the day comes and now you're aware. But it's usually followed up with a whole lot of absolutely nothing. There's no substance to it. And that's why for us it's like a benign celebratory day where it's like, "Hey, we're still here!" But, what it could be, to your point and to your friend's point is something exactly like what you just described. Where, I mean you're gonna need more than a day. But March is CP Awareness Month. And so, take the month of March and every single day, do something. Like, "Oh here's a video about why having CP sucks. Here's a video about why it's actually pretty cool sometimes. Here's a video about pain. Here's a video about speech impediments." Blah blah blah...Because it's such a broad spectrum in terms of disability, that I think you need that. I really do. There's not enough.

Emily: Well, I mean on the one hand, I don't want to say that it's your job to educate everyone about it but on the other hand, you know if you really want awareness to stick and then move beyond awareness then you're gonna have to do something about it.

Kyle: Yeah no, I actually, I mean we've talked about this. I love educating people, I do I *really* do, I think it's my favorite thing. Like when I see someone get something it's like "Yeahhh!" But, my problem, cause I'm lauding it so I have to be fair to the other side. My problem with World CP Day is that it inadvertently puts people with CP up on a pedestal. It's a cool "in" joke if you have CP, but if you're a parent, or a lover, or a caregiver, or a caretaker... or anything that's not an individual themselves? It's like you know, "I bought this shirt cause I love someone with CP today!"

(Emily laughs)

Kyle: And it's like, I get it I get it I get it... I get it and this is the only day of the year where that's even remotely acceptable so I get why you do it today, it's World CP Day. I totally understand. But...

Emily: Doesn't it also kind of make you feel like a charity case at all? Depending on...

Kyle: That's the...yeah! It's like, dude! You know when I know we'll have achieved CP enlightenment? Is when there doesn't need to be a World CP Day anymore. You know, World CP

Day is run by one of the best CP charities in the world. CPA in Australia (Cerebral Palsy Alliance) Their tactics are questionable, I know someone is gonna say that, I know. But they get stuff done and it's good stuff. They put out a lot of information, they put out a lot of content, it's all generally very good. But they put out this video for World CP Day, and it was aghhhh so frustrating..it was like so close, they almost had it. It was this video of a globe and it zoomed into every country with someone with CP. And first of all it was a whole bunch of individuals with CP and I was very hopeful. And then it started zooming in on it's like, "Oh my son has CP and he makes my world!" It's like, yeah of course he does! He's your son! It's not because he has CP!

Emily: This happens all the time. Like with Down Syndrome?

Kyle: I know but it just eludes it! It eludes it, it makes it worthless! Of course you love your son you idiot! What's wrong with you?

(Emily chuckles)

Emily: Like for Down Syndrome Awareness um, I remember a couple of years ago they released this whole ad campaign or like PSA thing where it was a woman with Down Syndrome narrating the advertisement about how she lives a totally normal life. But then it had a famous actress.

Kyle: Oh my God the uh, the Olivia Wilde thing?

Emily: Yes!

Kyle: Oh my God! That's another thing, it was almost there! It was almost there.

Emily: I was like, so furious about that. And even some people who I feel like usually understand the whole disability thing were giving me crap for being angry at that ad. And I'm like, "This is doing nothing to further education or awareness! It's basically just saying that disabled people aspire to be non disabled models and actresses "

Kyle: I think that's taking it a little literally but I, I was in your corner when that rolled around.

Emily: Well..no. I obviously had a more nuanced argument against it than that, you know..

Kyle: Oh, and and your third point by the way was how I brought up medical awareness, as long as we were still trying to remember what I was saying.

Emily: Oh, good. We'll definitely get to that. But like the other thing

Kyle: Oh sorry I thought.

Emily: No, don't be sorry, there's just so much to unpack!

Kyle: So much to unpack here!

(Emily laughs)

Emily: Um, so I think the other thing too is. I always say and I'm kind of just having this revelation now. Like oh, "We need to move from awareness to acceptance." But no, I think right now we need to move from awareness to education, because when I was in college I remember being very, very angry because Disability Awareness Week um, just was this series of a waste of events on my campus. I don't know if I've told this story on the podcast before, but I actually

had one of the Resident Assistants in my building ask me if she could use my wheelchair for an awareness event and let other people ride it around. And that was infuriating to me on like, ninety-six different levels. And like, I got real fired up about how awareness is a waste of time. And it was also juxtaposed with Alcohol Awareness Week.

Kyle: Yeah

Emily: And so, I wrote an Op-Ed for the newspaper where I was like, “Listen, guys you know I understand you want people to be aware of disability but you also want people to be aware of alcoholism, and it sounds like you’re saying that both of them are a problem.” *(Sighs)*

Kyle: I think you did mention that in the college episode but,

Emily: Yeah

Kyle: It’s certainly bears repeating here because it focuses on the issue right? I think the people who ask you to borrow your wheelchair for a demonstration are the exact people who need awareness. Like, you know, if you take a wheelchair away from someone who uses a wheelchair to get around, what you’re doing is you’re taking away their ability to get around. That’s a lack of awareness.

Emily: Well, she wanted my spare wheelchair...Not my spare, like I had a manual and a power wheelchair and she was like, “Can I just borrow your manual wheelchair for a little while?” “NO! You may not borrow my expensive piece of medical equipment for your stupid event.”

Kyle: Right, but that’s still a lack of awareness. It’s slightly less bad, sure okay glad you gave her that little olive branch but like still, it’s not that much better.

Emily: But the thing is that I’m so busy railing on about, “Oh we don’t need awareness, we need to move from awareness to acceptance.” But the reality is we need to move from awareness to education because, okay, you’re aware of me, now what? Like maybe you need to have some greater understanding, and awareness does *not* equal understanding.

Kyle: Acceptance is at the end of awareness. Acceptance is the last step, you’re done. If you have acceptance you don’t need awareness any more. That’s..

Emily: You’ve reached the end of the path of enlightenment

Kyle: For disability. I mean it's different for disease like we said. But like, strictly for disability, when you're done with that, when you have acceptance, there's absolutely nothing you need an awareness day for anymore.

Emily: Well, I don't know if that's entirely true because you can be accepting of disabled people and still be a complete jerk around them. It's accidentally.

Kyle: Yeah, but that's just being a jerk! ...Yeah okay, you're right you're right, you're right! That's why we still have..

Emily: So the reality is, you need education! No matter what, you need education.

Kyle: Absolutely and that's probably why we still have months for alcoholism for example. Everyone knows it's bad.

Emily: But why is alcoholism awareness? Why isn't it "Alcoholism Education Month?"

Kyle: Because that would imply having to do something, Emily. Everyone likes to just feel good. So if they change their profile picture to...to some you know, color filter they're gonna be like, "I'm helping!" And you're not helping.

Emily: Thank you for giving me my transition to my next thing.

Kyle: You're welcome!

Emily: Much appreciated boo! Like, stop buying pink things, Oh my God! I mean, in general... Maybe I'm just bitter because Larsen's Syndrome really doesn't have a color because..

Kyle: Aw you're mad?

Emily: Yeah maybe that's what it is?

Kyle: CP has a color, it's pretty great.

Emily: Yeah, I know you guys are green. But really, what does wearing green accomplish? Because green is also the color for St. Patrick's Day...

Kyle: Oh my God

Emily: It is also the color for environmentalism. Like what does it accomplish?

(Emily groans)

Kyle: Well okay, Emily but there's only like twelve colors. *(Emily groans, Kyle chuckles)* But also, you know, CP awareness month is in March, okay and green is our color. Okay, someone didn't think that through. I'd like to take whoever thought that out and bring 'em out to the barn and maybe shoot them. *(Emily laughs)* because that's dumb. Um, but yeah no, you're right, you're right. Colors, I mean the most that they do is show someone who is walking down the street a bit of solidarity, and you you're taking that with a grain of salt because they could also just be happening to wear the color that your cause is for, you know? But that's about it.

Emily: It just feels...I think you used the word "hollow" before right?

Kyle: Yes, I did

Emily: And it feels hollow to me. I mean, or like around World AIDS Day in December, in high school, they would have us all wear red and they would have an assembly where the choir sang songs and we watched videos and we gave a presentation. Is any of this registering? Because we all had to wear red are we actually aware of the actual consequences of unprotected sex?

Kyle: I think that when you wear a color, and I know I've shi**ed on wearing a color before in the Women's Day episode, and my views haven't changed but I will concede that I think that if you...if somebody's wearing a color on a designated day *and* they know what day it is, then you can look at that person and go, "Okay, you're an ally. I don't need to...you're not the person who this is for. This is for everyone who doesn't wear the color." But that's dumb too! I don't know, I agree with you, it's dumb. Even when I try to justify it I can't

Emily: Okay here's another super egregious example: Light it Up Blue. Autism Speaks

Kyle: Yeah well..I mean, that's gonna be, we're gonna get half love and half hate for that

Emily: Hate me if you will but I think there's...

Kyle: I don't like Autism Speaks. I don't like Autism Speaks either. I don't.

Emily: They're the worst offenders! Other than breast cancer, they really are. I mean literally, they get the Empire State Building to light it up blue and yet your awareness of people wearing

the color blue does *nothing*. You know what it does? Literally nothing. You know what would be better? If we would educate people *about* autism.

Kyle: Yeah, spend the money you spent on lighting up the Empire State Building blue on like, anything else and you'll do a more better...uh, more better? You'd do a better job.

Emily: Not a cure.

Kyle: Yeah but like, even if you researched a cure like, even that, is more useful than a lightbulb

Emily: That depends on who you're talking to.

Kyle: It's not more useful...it's more useful than a lightbulb. Even if you disagree with it, which I do.

Emily: Oh yeah they sell blue lightbulbs right?

Kyle: Probably

Emily: No they do, I've seen them in like Home Depot

Kyle: Oh, do they?

Emily: Yeah. you know when you wanna like, light your house kind of in a mood lighting situation? The blue one becomes for "Autism Speaks" or something I think.

Kyle: Yeah, but I hate that because I like the color blue and I don't like Autism Speaks so like, leave me out of this.

Emily: Same goes for pink. I find it completely infuriating. I mean, I think that if you are a cancer survivor who has come to embrace the color, then I have no right to step all over you for doing that. But the people who think that they are doing a good deed because they bought something pink and the money goes to the Susan G. Komen Breast Cancer organization...

Kyle: That's a horrible charity too

Emily:Like are you kidding me? It does nothing. It does next to nothing, it does actually nothing.

Kyle: I, I know..and we're gonna get comments cause we always do, cause we did on the Women's Day episode too so someone's gonna be like, "Well actually" and I'm like "No, dude you well actually" okay because when I go out and buy chocolate syrup and the little cap where the syrup comes out is pink for Breast Cancer, all that's doing is making me look at that bottle of chocolate syrup and go, "Huh!"

(Emily laughs)

Kyle: It's not saving a life,

Emily: Yeah!

Kyle: And I know all about breast cancer. I know it's terrible, I like you know...Cause every year The Susan G. Komen Foundation...

Emily: *You* know all about Breast Cancer? Okay, please tell me.

Kyle: Nobody knows more about breast cancer better than me!

Emily: *(laughs)* Whoaaaa, okay

Kyle: No, I don't. But my point is I don't, and yet every year I know when the pink color month is, I don't even know what month it is! But boy do I know when it happens. That's my point! Like you would think after all this time that has passed that we've seen these pink ribbons and...and caps of chocolate syrup bottles that you and I, Kyle and Emily would know so much about Breast Cancer that we'd able to recite an essay about it to someone on the street and yet, we don't. Cause awareness campaigns with colors are bulls**t!

Emily: Oh my god, that's exactly right. Like, it's become innocuous. It's become utterly..

Kyle: Stupid! Dumb!

Emily: I don't know what...I don't know.

Kyle: Ridiculous

Emily: I was gonna say arbitrary

Kyle: Laughable. Arbitrary. ...You *(unintelligible)* the color pink!

Emily: No but it's just like, I get that you're trying to support a good cause. It might even be this month! I don't know..

Kyle: Oh sh*t...is it?

Emily: How am I failing so miserably at knowing? You know why I'm failing?

Kyle: No, it's like, that's like "You're failing Emily!"

Emily: I don't know anything!

Kyle: No, it's stupid.. This is exactly why it's stupid. You were right when you said what you said before. Anyway, so that was point two, of our three point plan

Emily: Oh, are we done...but are we done ranting?

Kyle: I don't know..I think awareness campaigns assigned to colors are stupid. I think awareness campaigns are important but if all you have to show for it is a color, you have failed at life. Get a different hobby. It's dumb! It's stupid!

(Emily laughs)

Kyle: Go away!

Emily: I feel really bad if we have any like, marketers listening to us whose job is to do this

Kyle: You should feel bad! You should feel bad...take it from somebody who's a marketer. It sucks!

Emily: *(laughs)* Um, okay so now that we just took a crap all over color awareness um...

Kyle: Colors are a social contract! No, they're not

Emily: You know, I feel like it didn't used to mean something until pinkwashing happened. I think there was a time in our lifetimes where this was just starting to become a thing. And it wasn't so arbitrary.

Kyle: Yeah for sure. And you know what? I actually, I don't blame them for genericizing themselves cause they got so big that they didn't know what to do with it literally so they just put

it on everything. Like, if that's your charity...I mean I know it's a bad charity, I know that. But if you're the head of it before it got bad then you're gonna think that you hit the lottery! Like, that's exactly what you want, you wouldn't dream of that amount of awareness! But the fact of the matter is, it's hollow. Because all we know is, "Oh look that thing's pink." We don't know anything about Breast Cancer.

Emily: Yeah and not for nothing, but I feel like every pink item that is sold should come with a guide to breast self-examination.

Kyle: Oh my God, yeah! See, that would be useful, so they'll never do that.

Emily: Because to be quite honest, like until my mom said to me one day, she's like, "Are you feeling your boobs every once in awhile to make sure you don't have cancer?" I'm like, "You know what mom that's a great point."

Kyle: Similarly was like, "No Shave November" that's for Testicular Cancer. I went like, most of my life knowing about "No Shave November" but having zero clue that it was for Testicular Cancer. Like, none. I just thought it was a thing that men did in November.

Emily: Yeah, and you need to what like go get a prostate exam or something like that? Or like...

Kyle: Yeah. Yeah. And that's great! But no one know's that. And I don't think I'm...I mean I'm not gonna say that no one knows it because I didn't know it but I really think that most men don't know that. I think that most men just think it's "cool."

Emily: Oh! Or...we have to have talked about this before but the "Ice Bucket Challenge" for ALS?

Kyle: Yeah but that was...that's a little different.

Emily: Although, that raised *so* much money

Kyle: That raised so much money that they charity, bless their heart doesn't know what to do with it. Still, years later. So yeah I mean...but that's a little bit different because that was a hitch that took off like wildfire. That was just...A hunch, rather

Emily: I just wish that any campaign like that was also associated with education. Awareness and gimmicks are exhausting and useless.

Kyle: Yeah but and I'm not even...it's not even that gimmicks are like, bad right? Cause you need that. That's the hook that you need to get the attention of somebody to bring them into the awareness. But if you're not following that up with the education, you're just being coy and cute...Like it's nothing...it's fluff.

Emily: Yeah, but like, what are you doing with your gimmick?

Kyle: It's a cake with just icing and no cake. It's just like there's nothing, it's...

Emily: Oh, and not for nothing but I don't really like icing so that would be the worst cake ever.

Kyle: Yeah, word.

Emily: That would just be a container of icing.

Kyle: Exactly

(Emily laughs)

Kyle: The third thing I said was medical awareness. And I think CP is...and I know, I know the disability community has like a love/hate relationship with medical stuff and I get that as somebody in it but like, CP needs medical attention in a huge, big, massive way. And there's no ifs, ands or buts about it.

Emily: Well this goes for disability in general. I mean, I realize there are a subset of issues that are unique to CP but everything from etiquette when it comes to working with a patient with a disability, to understanding the complexities and nuances of a disabled body. I think that that's the type of awareness that we need. Again, that's really not awareness, that's education but there is nothing that puts me...or makes me feel more ill at ease than an unaware doctor. And I'm not saying for me, like I...It's different for me than it is for you. Because if a doctor does not know what Cerebral Palsy is? That's like red flag... why do you have your medical degree? But if um, a doctor doesn't know what Larsen's Syndrome is? Like, I'm more willing to be like, "Okay it's really rare so I get that you don't know what it is." But, there's something to be said for having an understanding of how to work with patients with disabilities and that's where I think awareness campaigns could focus their effort, and yet I don't feel like they do.

Kyle: Yeah, yeah. And I...It's funny because they assume...Well, it's not funny, but it's like "funny" because that in particular is, if there's one puzzle piece missing from this whole mess? It's that. It's like we're a population of people that needs to go to a doctor more often than people

without disabilities. I don't know if that's true, but it wouldn't surprise me in the least. And yet, something like 80% of all new medical grads have never spoken to a patient with a disability? Like how are you even.. that should be in your schooling! Etiquette for the population that will frequent the doctor more than any other kind of people probably. Why is that not part of your curriculum?

Emily: Do you know what scene I really want to break into and I really can't figure out how? I wanna speak to medical students. Like, I did it like a little bit with my mom when we were younger like, about Larsen's Syndrome. Like, I know when I was younger we filmed some kind of a video for some medical students or whatever. But I mean, I talk to a lot of occupational therapy classrooms, um and stuff like that. Actually never physical therapy classrooms, so hit me up, PT professors! But um, more than anything I want to talk to future medical professionals to be like, "Hi, I'm a real patient that you're gonna need to handle someday and here's how you do it without being an asshole about it"

Kyle: Yeah, absolutely.

Emily: Can we market ourselves for that?

Kyle: Let's do it man. But, the reason I bring up that for CP in particular, and I know it's like that for every disability, but it just so happened to be CP Day. And I don't think what I'm about to say is unique to CP either, but...CP is a medical condition that has vast oceans of information if you're under eighteen. And when you're *over* eighteen it's just gone! It's gone! No one knows anything about adults with CP. I almost said "CP Adults"... that identity first language. But um, nobody knows anything, and it's like our birthday was yesterday. What happened? Nothing changed in the twenty-four hours between the last day of seventeen and the first day of eighteen. And yet, the medical knowledge is just...it's sparse. And I'm not gonna sh*t on it entirely, there are some things, and some of those things are very important and slowly but surely there are more trickling out and I'm so grateful for it, it's not even funny. But like, I shouldn't have to...it shouldn't have to be like "The Third Coming of Christ" when a new paper about adults with CP is published, it shouldn't be a huge deal. And yet, in this community, it is. It's like, "Oh my god check this out! Holy Sh*t, something happened! Look we can detect it six months earlier, is that cool?!" And then there's some people who don't think that's cool. But I think that's cool! You know and it's like...yeah I mean that's not for adults but that did just happen so.

Emily Isn't that for disability in general like, everything is so incremental when it comes to medicine? I don't know, and I understand that's it's a lot for doctors to keep up with *every* disability but I don't think it would hurt to have a working knowledge of certain disabilities. And

so, while we're all busy selling our pink frosted cupcakes and our green tinted tee shirts, there are legitimate issues that we could be solving

Kyle: If the...if the revelation for Cerebral Palsy making it, increasing the quality of life in whatever way you hearing this deems best for you, because it might be different for me, if you also have CP. You know, if that doesn't happen in my lifetime or in your lifetime you know, what's the point? I mean I know the point is for the next generation or for two after that but you know, I don't think it's totally unreasonable to want something that stemmed from some problem that you know I didn't know about. Like, my being in pain, that was... I learned that three years ago. And..and no doctor knows about it. If I tell them, "Oh yeah half of people with CP live in chronic pain" they go, "Oh, really?" It's like, "No, you should know that before I know that!" Right? But I don't think it's unreasonable to want an increase in your quality of life within your lifetime. And that goes for any disability. And that doesn't have to medical although for me it pretty much is. But that something, whatever "that" is for you, is something that can be the result of awareness campaigns, but instead we're just frosting our cupcakes pink!

Emily: Well I think that's the problem is like we lump all of this "stuff" into the category of awareness, but awareness is so many different things. It could be awareness of how to prevent a fatal disease like Breast Cancer or AIDS. Or awareness that you are not alone in the universe and there are other people out there like you. It could be awareness on the fact that, "Hey, disabled people exist and maybe don't treat them like an imbecile or someone that is less than human" You know? Act like a person around them! Or it could be awareness like, "Hey, you're a doctor you're gonna have to see disabled people, here's how you treat disabled people." I mean, there's just so many aspects of awareness, and I don't think that most awareness campaigns ever get to the heart of any of those issues.

Kyle: Yeah. By the way, while we're on the subject is there something you know about Larsen's Syndrome that you think other people should know about Larsen's Syndrome?

Emily: *(sighs)* That's a great question, umm I don't know. For me, it would mostly be what I want doctors to know. But, I don't know. I guess maybe a lot of people see someone with a disability and automatically assume that they like, are paralyzed or don't have feeling in certain parts of their body. And I want people to recognize that Larsen's Syndrome, while it does involve your spine, it's not a paralyzing disorder, and it's not a disorder that affects feeling.

Kyle: I didn't even know that. And I know you. And I know you feel, but I just..you know

Emily: Yeah like it can affect many things and it manifests differently in different people. And in certain instances um, some of the symptoms of it if they're severe enough, can be fatal. Like, I

know a little boy who had the heart defect issue that came with it and he passed away so...but yeah, a lot of people like their first question, and this is just like a disability thing in general. Like if you see someone in a wheelchair? You're just like, "Oh they must've been injured or they must have no feeling from the waist down" And that's not true of all disabilities. I don't know. But like, the other things are such little things, that that's why I don't know that Larsen's Syndrome Awareness Day would be useful. Honestly, it would be more useful for me on a level of like, I get so excited when I know that other people with my disability exist. So for me, I think it would be more celebratory than anything else.

Kyle: Mhmm. Well that's why we like World CP Day. My thing with CP is, I learned this through a former employer, and this is totally true and it's scary, but as long as we're shi**ing on Breast Cancer, or Breast Cancer Awareness, excuse me. Let's sh*t on Breast Cancer too, cancer sucks f*ck cancer! If you're a woman with CP, and you have Breast Cancer, you get diagnosed with Breast Cancer, you are three times more likely to die from it. Not because of CP, because you are, by virtue of having it, and you know, the things that that does to your life. So inaccessibility in general for instance. Because you are less likely to then go to a doctor, you are likely to die from it simply because of inaccessibility and lack of medical knowledge. And *that* is, "because of CP" but not because of CP. But it's true, that if you have CP and you get Breast Cancer, and you're somebody with breasts...well, everyone has breasts. But it's specifically that you're three times more likely to die from it, and that's scary!

Emily: Well, while we're on the subject of breast cancer and I...

Kyle: Check your boobs everybody!

Emily: Yeah, but also like, *everybody*. Because men can get Breast Cancer too. And that's another thing, like that's why it needs to be education and not awareness because we have pinkwashed the crap out of Breast Cancer so that means that you know, a guy is probably less likely to be on the lookout for that.

Kyle: (*unintelligible*) Yeah, sort of semi-related but, Prostate Cancer is like, way more prevalent than Breast Cancer and like I said before we don't get a color, we just you know..I'm not saying it's more important just because it's more prevalent, but I'm just saying it's weird how the marketing of one charity has infiltrated the "Awareness Market."

Emily: I don't think anyone's ever gonna replicate what the whole "pinkwashing" thing has done.

Kyle: Oh, no no no. You know and I think that at this point it's actually gotten too big for it's own good like you were saying earlier. I think that they just have achieved so much success that they don't know what to do with it, although I don't like them as a charity, I can sort of see why that's not an enviable...an enviable position to be in

Emily: Does Prostate Cancer have *a* color?

Kyle: I don't know. Probably. But I don't know!

Emily: I mean, that says something in and of itself, when you don't even have a color association with it. But also, I don't need a color to tell me to check my boobs.

Kyle: Yeah but, like you said before I mean how.....Did you know to? I mean, I know you do, but like, when did you learn that? Probably a little later than you should've, no?

Emily: Um, from my mother and I don't think we have it anymore but for a very long time in our shower we had a sign hanging up that showed you how to do a breast self-examination. And I think that kind of peaked my curiosity one day. So I was like, "Oh, I should do that! I should make sure that I'm okay." And you know, my mom also talked to me about it and things like that. But that card in my bathroom did not have a stitch of pink on it. It was purely scientific, preventative information.

Kyle: Good! I know..I know it's marketing, I know ya gotta make stuff look pretty otherwise people won't pay attention to it but like still...

Emily: There's a strategic way to do that though, and the strategy has been lost.

Kyle: Yeah, I'm..I'm totally with you there.

Emily: So, at the end of all this do we even know what awareness really means? Or can we come to some kind of consensus on our feelings about awareness?

Kyle: I think you summed it up pretty nicely before actually when you said that awareness has multiple meanings depending on the kind of disability that you're raising awareness for. Like, you said the kind of awareness you care about is actually knowing that other people with Larsen's Syndrome exist. And you get all giddy and excited when you see someone. So in that respect, a "Larsen's Syndrome Day" would be beneficial to you. Whereas for me it's like, "Yeah CP's a thing, awesome!" And I'm all about that too because it's so common but also I really do care more about medical research than just *knowing* I have CP. I don't care, I already know I

have CP, I don't need a day to remind myself, and I guess I would say too that I really do think awareness campaigns are absolutely necessary. I think you know, if you're someone who really thinks they're useless, you're a bit of a cynic. But I think the reason that you became cynical if you're one of those people is that they are so often followed up with absolutely nothing else to show for it. And that is the problem, not the awareness itself.

Emily: Or they're just done very poorly.

Kyle: Yes.

Emily: I think that there are so many attempts at awareness out there, and I could probably rattle off a ton of them that ultimately don't accomplish, yeah they don't accomplish what they set out for.

Kyle: Yeah

Emily: And that's what really gets me about awareness campaigns. And um, for the people who have listened this far, I'd be interested to have people share with us what awareness campaigns they think were successful versus the ones that kind of fell flat.

Kyle: I agree. And we'll try to find some to put in the video description...in the podcast description! The show notes. Um, do you have any final takeaways?

Emily: Yeah, stop focusing on just awareness and stop saying that it has to be all about acceptance because then you're missing the crucial step in the middle which is education. So I am now going to be all for education.

Kyle: Yeah, I echo that 100% I, you know I said it before. Most awareness campaigns are like a cake made out of icing. No substance. And I think that that's more of a problem than the campaign itself. Usually. I mean there are some bad campaigns out there of course, and there are some.. you know. But I think that usually with such a thing that your hearts are in the right place and I get that. But um, you know it ultimately falls flat for a lack of follow through more than anything else.

Emily: I think it can be the flip side if we're going with the cake comparison. Where it's the cake without the icing too. Because, that's an incomplete cake.

Kyle: Yes.

Emily: And that's often what happens with awareness is it's very half-baked.

Kyle: You're right, you're absolutely right. There ya go!

(Both laugh)

Kyle: Baking metaphors everybody! Aw man///

Emily: Now accepting pink frosted cupcakes. Please, I would love a cupcake.

Kyle: Yeah like with buttercream icing, please?

Emily: Buttercream makes me feel kinda sick, I like Betty Crocker icing.

Kyle: You're terrible. I will eat buttercream icing. Feel free to send it to our P.O. box that isn't really...

Emily: I usually pick the icing off my cake. I usually just eat the cake.

Kyle: Please... you are...the worst person I've ever met in my life. I cannot..

Emily: Like, if it's an ice-cream cake, I just eat the ice cream.

Kyle: Yeah well, that's different because ice cream is better than cake. Like ice-cream is like...don't ruin two good things by making it one bad thing!

Emily: Like, but if it's a cake I usually don't like the frosting. Um, except in very specific circumstances like,if it's like a coconut cake then I'll eat the frosting.

Kyle: You like coconut?

Emily: Love coconut!

Kyle: Me too. And on that note..I am Kyle, she is Emily, this has been another episode of *The Accessible Stall*

Emily: Thanks so much for listening!

Kyle: See ya next time

Emily: Bye!

Kyle: Bye