First Voice

November/December 2021 **Issue No. 0002**

Diving Into 2022

By: Gerianne

Wow! We're really diving into 2022 already... Wellllllll ssssugardaddy! ☺ lol

In the first issue of First Voice, I used another "shhh" sounding word and evidently I used that certain word 3 times - all in the same article. Sadly though, exercising my freedom to use that certain "shhh" word did cost me some readers and promotional support.

Initially I was shocked and dismayed by the reaction, and I felt torn. While I do understand this assembly's viewpoint and I certainly don't want to offend any of my readers, I felt on thin ice with this dilemma. Where should censorship begin, and where does it end? It can so quickly turn into a slushy mess. Another organization or individual may get offended by another word, and so on. Before long, I risk losing my own "first voice" and personality.

So the conclusion I've come to is, while I'll try my best not to offend or alienate any reader, "I gotta be me."

See, unlike other publications where I've played a leadership roll but I was part of a team and what I said and did reflected on others, this "First Voice" news-zine is solely mine (and Mary's). In my mind & in regards to this publication and DisabilityPride.net, Mary and I are pretty much partners, not officially and not legally, but partners in spirit.

Lately I've been thinking a fair bit about the year that was 2021 and for me, it really felt like a year of misfires, with underwater missiles shooting up spectacular fountain-like explosions all around me; and

while some people may think of this imaginary as beautiful, for me it was an extremely frustrating year.

As 2021 rolled in, I was still enjoying a financial buzz from my success on Facebook Marketplace during fall of 2020. Feeling pretty good about how well it had gone, plus also feeling like I had a solid staffing situation attendant-wise, I collaborated with Mary to get 2021 off to an enthusiastic start!

We had plans of making this a quarterly news-zine. I had plans to get serious about working on my autobiography. Mary had intended on writing more content for our blog, plus we had several other ideas to put into action.

Well, we all know at least one popular saying about us humans and our plans: “The best laid plans of mice and men often go awry.” and “Want to make God laugh? Tell Him your plans.” We all kid ourselves about our “delusions” of having control over pretty much everything in our lives; but the truth is no matter how much planning we do or how determined we are, things beyond our control happen. Dr. Phil McGraw is quoted as saying: "Willpower is a myth. The problem with trying to use willpower to achieve...is that it is fueled by emotion. And as we all know, our emotions are, at best, fickle. They come and go. When your emotions start running down -- and they will -- even your best-laid plans will fall flat."

I think about such things from time to time, and anymore I laugh on a rare occasion when a doctor or a nurse asks me: “Gerianne, do you have full control over your bladder and bowels?” Without thinking, I offensively answer: “Yes! Of course I do!” But then in conversations with friends and others, someone once told me about how badly they “had to go” in the middle of a long drive. They stopped at a gas station a.s.a.p. but it was already too late. The person felt awful about doing so but they ended up having to put their soiled underwear in the restroom garbage.

I once had an attendant who, at the start of pretty much every shift, would come running into my apartment on her phone, screaming at one of her kids and hang up with an abrupt “I’m at work now!!!” She’d then announce to me: “Gees!!! I gotta peeeeee!!! If I don’t go right now I’m gonna pee right on your floor!”

I once got so fed up with her doing this, that I one day said: “Stop! Would *you* mind if *I* use *my* bathroom first? Would that be alright with *you* - if *I* actually use *my toilet* before *you do*?”

On the other hand, I had another attendant who also had small bladder issues (in fact it was a medical condition for her), but when she came she was polite and would always ask if I’d mind if she’d “go first.” One morning she came in carrying a huge pack of toilet paper. When I asked what the heck

she was doing, she said: “I figure I use soooooooo much of your toilet paper, I want to replace some. I fondly told her that she was a silly goose.

So I’ll ask again, who really has control - over anything? Even in the general arena. Since COVID, how many weddings, trips, graduation ceremonies, and endless other events have had to be altered, postponed, or outright cancelled? It seems to me anyway, that those who believe they “have control” have delusional thinking.

Now, by no means am I even hinting at suggesting that we not plan. Of course we should plan, dream, schedule and all those great things. We should dream BIG, plan a lot, and have an abundance of hope and positive thinking, but we should do so with an open mind and a willingness to be flexible. After all, if we become too rigid in our focus, we can miss seeing other amazing opportunities that are coming our way.

I tried not to get too cocky at the start of 2021, but I’ll admit I had high hopes. Soon though, the interruptions and challenges came piling in, one after the other. An attendant quit suddenly. I don’t think they meant to but they had severe mental health issues that just got the best of them. Although things ended very badly, I still think the world of that person.

Trying to find staff with a suitable attitude and who’ll be a good fit for this job is often a very long process. First, because I have many non-conventional beliefs and values, those whom I hire need to be kind of unique as well. Some try. Yet as much as I may like them as a person, they end up just not being a good fit as one of my attendants.

Yet my search for the right staff is certainly not unique to me. I used to think it was, until I spoke with an employment person who (before retiring) spoke with hundreds of employers every week. He said that across the board, the vast majority of applicants don’t even show up for their initial interviews. That’s certainly my experience. But even after the initial interview, my staff need to do a few “shadow shifts.” Depending how long it takes for me to feel comfortable with them, will determine the number of shadow shifts required. At any point the new staff may determine this job isn’t for them. Occasionally a person will simply never come back, without a word, to complete their shadow shifts. They simply vanish. Then it’s back to square one. It can be a long, exhausting, and frustrating process, but one well worth it, because the right people are gems - rare finds - and I value them tremendously. My attendants are a vital part of my daily life. They need to be punctual, reliable, open-minded, willing to listen to me, and honest, because for instance, if they don’t come to assist me with getting up, then I’m in bed until the next person comes, in which case most things on my “to do list” for that day will likely be scrapped; not to mention my health

may be at risk. Not being able to use the washroom for 10+ hours can lead to UTI's and/or kidney infections.

By early summer I felt that Mary and I had found the answer. A young person who I had been close to wanted a full-time summer job. So we created one for them. Mary and I put a lot of time and effort into making it beneficial for all of us. We presented the details in print, gave that person ample time to really consider things before signing "on the dotted line." Yet it seemed that before the ink was dry, this person started making unreasonable "requests" - cut backs in hours, every weekend off, no morning shifts, and other such things. Mary doesn't even get those things. The person became more and more argumentative with me. It became a daily heated debate. Then they quit on the spot. By this time it was too late to hire another summer person. We tried, but to no avail because at that point practically all the youth either had their summer jobs, had gone home for the summer, or didn't want to work.

So, we had revenue streams ready to go, but no staff to help Mary and I promote them; plus when that person quit so suddenly we were then down a part-time staff. I was devastated and so discouraged.

Entering late August and after hearing two of my church's leaders talk about "interruptions," I felt somewhat better. These interruptions that seemingly all too often come our way, may just have a purpose - whether it's taking time from our own agenda to help someone else; or allowing time for our hearts to heal; or giving us an opportunity to rethink and refocus. There's usually a broader reason for the things that are making us pause. It's usually not just a waste of our time, although we may think so.

So since then, both Mary and I have been trying to get "admin" tasks completed and out of the way, with the hopeful plan that in 2022 I'll be able to seriously work on my autobiography (yes, again) and Mary can further develop content for DisabilityPride.net.

One thing I've always liked about the start of each new day, each new week, each new month, each new year and so on, is the opportunity to reboot with fresh energy. So with that in mind, I'm looking forward to 2022. I hope that opportunities will abound for you as well.

Battling Guilt and Internalized Ableism as a Parent

By: Mary

Accepting the label of "disabled" is a struggle for me. Both of my children have disabilities but they are invisible disabilities. Also, my children haven't ever referred to themselves as "disabled" and I am reluctant to label them with an identity that they did not choose for themselves. That makes my experience of a mother to disabled children complicated when it comes to self-identification.

These are separate struggles intellectually but they combine into my guilt and anxiety about being a mom with disabled kids. I can and will readily talk about their disabilities but referring to my children as disabled makes my skin feel itchy. Then there's the issue I have identifying myself as disabled (mental illness is a disability, I have to keep reminding myself of that).

I am examining my internalized ableism every day and doing my best to acknowledge it. We can't do better unless we know better and we can't know better without examining the problem. As someone who grew up around a powerful disabled community filled with people with wide ranges of disabilities that impacted their lives every single day of their lives, I don't tend to think of myself as ableist but that's just naïve of me and I struggle with preconceptions and prejudices every day. My big struggle is in comparing the lives of myself and my children to the lives of other disabled people and not feeling like we have "earned the right" to identify as disabled.

This use of the idea of "earning the right" feels like internalized ableism but I cannot tell you why. It also speaks to my concern about appropriating labels and ideas that I may not fully understand, something I have tried to avoid unless I'm trying to actively antagonize someone with a narrow world-view. There are times when it's appropriate to "know my place" but for the most part I am of the opinion that my place is wherever I happen to be at that moment in time, that I am where I need to and deserve to be.

So, how do I work through my internalized ableism and give myself the right to use the labels that best apply to my kids and myself? That's a question I ask myself frequently and I don't really have a universally applicable answer. My personal answer seems to be to just use the words that feel the most comfortable and appropriate at the times they feel most comfortable and appropriate, which is another way this feels ableist or at least able-body passing privileged. I am not forced to acknowledge my or my childrens' disabilities unless I/we choose to.

Struggling with identity, feeling guilty about parenting decisions and struggling with

internalized ableism are common experiences for most people in a similar position to me. I don't think there is any one right way or right answer to solve these problems. I'm not even sure they are actually solvable. It's through frequently examining my self and reflecting on how ableism impacts my life that I grow and build an anti-ableist life for myself and my kids. If I'm not willing to consider that I'm making mistakes then I'm not going to look for ways to be better or do better.

Contributors To This Edition

Throughout this issue of our First Voice news-zine, you'll see some beautiful artwork by Jessica Mcdonough, of Springfield, Missouri. We would like to thank Jessica for giving us permission to publish some of her original pieces for our readers to enjoy.

About Jessica:

Jessica loves to draw and paint. She has taken art classes for disabled people offered by the Art Inspired Academy, in Springfield, Missouri. Jessica really enjoys the classes and her teacher is fun to be around. Jessica also makes Goat Milk soap in beautiful designs and shapes. If you'd like more info you can email her at mcdonoughteddy@outlook.com or find her on Facebook.

Also Meet Emily

In this edition of our news-zine you'll find a really interesting article by Emily Woodside. Emily joined my staff on October of this year. You'll soon be hearing more about, and from, Emily. Currently we are planning to make an announcement about Emily's role in DisabilityPride.net early in 2022.

Meantime, and although 2021 was a frustrating year in terms of staff turnover, I am going to tell you that with my whole heart, I am immensely thrilled with my current staff of: Mary (whom many of you know by now), Alby, Cheyanne, and Emily.

Sadly, "Kelly 2.0" had to leave because of a health issue, but we're still in touch on facebook (as I am with most of my former staff).

Navigating COVID-19 With A Disability

By: Emily

The first time I heard the word "privilege", I was barely old enough to pronounce it (let alone grasp the entirety of its definition.) I was watching an episode of Caillou on my mothers lap, and it must have been around this time of year because it was a holiday special. Its focal point was the importance of aiding the less fortunate during the holidays. What I did understand was I had food, and

some kids didn't. I had clean clothes, and some kids didn't. What I didn't understand then, and still don't, is how it actually feels to be the less fortunate child on a holiday. No matter how hard I look at it and who I talk to, I will never understand what I don't experience.

Now that I'm older and can identify this bias, I hold more weight in the word privilege because I know it is a one sided mirror. I have access to one perspective and that is my own. This being said, I do my best to understand that everybody has different experiences and battles that I do not understand, so listening is important. Through listening to Gerianne alone, I have identified a privilege of mine which I had never considered: not having to navigate COVID-19 with a disability.

You would think in a society constantly patronizing people with disabilities, some empathy or consideration could be found in their unwanted pity. This pandemic has disproved that thought. Measures have been taken quickly and urgently by the government and citizens to adapt in this pandemic, leaving behind many disabled people who were not accommodated or considered in these decisions.

I first thought of this when I arrived at Gerianne's one evening to find she was discouraged. The reason being complications with her bank not cooperating over the phone, and refusing to service her "as long as Mary was acting as her translator." I had never considered that these security measures meant to protect people, exclude those with disabilities.

About a month or so later, Gerianne and I were discussing possible ways to evolve disabilitypride.net, and I had mentioned making the website more accessible to use on a cell phone, rather than mainly on a computer. "Whoever builds any website, needs to make it as disability friendly and accessible as possible." said Gerianne.

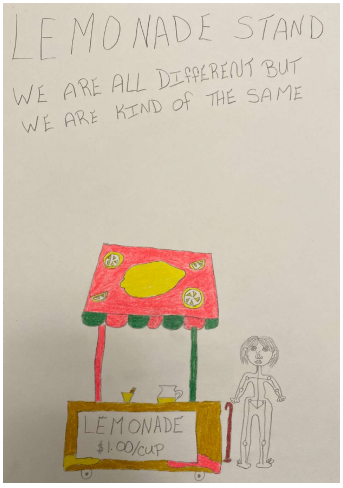
I was a bit surprised by this. Until now, I saw "disability friendly'' as physically accommodating infrastructure, and you can't add automatic doors and ramps to a website.

I took this home with me and did a bit of research. "98% of U.S.-based webpages are not accessible to the disability community from a legal perspective, according to the 2020 Web Accessibility Annual Report compiled by the accessiBe initiative, which analyzed more than 10 million webpages to determine their compliance with the Web Content Accessibility Guidelines (2.1 WCAG)."(https://isemag.com/2020/11/telecom-98-percent-of-websites-fail-to-comply-with-accessibility-requirements-for-people-with-disabilities)

This being said, covid has driven the digital era to flourish - meaning daily life is being transferred to a platform which is only 2%

accessible to people with various disabilities. If you think over-the-phone assistance is the alternative, that is clearly not the case given the recently discussed banking scenario. This same issue occurred again recently when Service Canada had a page not working on their website. Service Canada wanted Gerianne to "authorize" Mary as having authority "to speak for Gerianne". What the Service Canada agent wasn't willing to accept was that Gerianne was speaking for herself. Mary was simply repeating word for word, what Gerianne was saying. Gerianne was not giving up her right to express her own need, thoughts and directives. She was not giving up her intellectual independence.

I encourage whoever may be reading this to educate themselves on more of these covid-inflicted barriers by exploring accessiBe's initiative, following the CERB/CRB discrimination law suits, and delving deeper in understanding how covid-19 has widened the existing inequality. Let's make the world a more accepting place, and accepting means accessible. ☺



Kids and Invasive Questions About Disability

By: Mary

Every disabled person gets asked invasive questions. We expect them to some extent in the doctor's office, but the frequency of these questions from total strangers who have no role in medical care or personal living, is mind-boggling.

When does curiosity turn into a tool to control or belittle? I think it comes down to the old adage "Knowledge is power" and society is constantly disempowering disabled people. By taking knowledge, by assuming knowledge of someone else is theirs to take, one person is able to disempower another and turn the power balance from one of relative equality into inequality. By asking invasive questions the asker shows that they feel the asked is in a position of less power and owes them something.

I have a story about how I dealt with the invasive questions my kids asked when they were small. I have heard a lot of parents telling their children to ask the person who inspired the question about the differences they notice in other people and I have always tried to avoid doing that. People who are "different" in any way get asked these questions all the time and I did not, do not want my children to add to the emotional labour that comes with educating the public

about things that can be very personal.

So, we were in a grocery store and my daughter, who was about 3 or 4 at the time, noticed a Sikh man wearing a turban in the same aisle. She very loudly and excitedly asked "Mommy, is that man a GENIE!?"

I could see the man chuckle to himself and glace over in our direction, probably to gauge if we were going to approach him or if I was going to make some remark. I told my child "No sunshine, I don't think that man is a genie, I think he's Sikh. He's wearing a turban as part of his religion. If you're interested in learning more about it, we can read about it at home."

She forgot about it almost immediately and we did not end up learning about Sikhism. What I have always held in my mind when it comes to my children's curiosity is that when they are asking questions about a person they see, it is not that person's job to educate them. I have also done my best to help them know that they do not have to answer every question they get asked, unless it's me, their father or one of their doctors asking.

Both my kids have disabilities. At least, I consider them to have disabilities but I struggle with labeling them as disabled. This is for two main reasons: firstly, their disabilities are mostly invisible or "cosmetic"; secondly, they have not identified themselves as disabled and I don't want to force a label on them they don't get to choose for themselves.

We first encountered these invasive questions directed at us when my youngest bio child was about 3 years old. She was in the process of being diagnosed with Alopecia Areata and we were at a fundraising event for a friend who is also disabled. My child's hair loss was getting very noticeable and she, being 3, refused to keep her hat on.

It felt like every second person at this event came up to me, within earshot of my energetic, spirited child and asked "What's wrong with her?"

My answer, each and every time was "Absolutely nothing but if you're asking about her hair, she's probably got Alopecia which is random, unexplainable hair loss."

Her alopecia was confirmed and progressed to the point where shaving her hair was the next logical step. The first night we went to her sister's soccer practice after her haircut a group of kids innocently asked her "Where did your hair go?"

Like a pro she answered "My Daddy shaved it!" and left it at that. The kids were satisfied with that answer and they continued playing and watching their siblings.

She started school, sent with an information pack about Alopecia and the hope that her

teachers would be able to introduce the topic in a way her classmates would understand. That didn't stop her classmates from teasing her and being mean but she was more than able to stand up for herself with her quick thinking and occasionally sharp tongue. The teasing eventually subsided when they realized it didn't actually bother her that much.

My youngest bio-child is smart. She has a quick wit and the ability to understand relatively complex ideas quickly and with depth beyond what I would expect. It came as a bit of a shock when she was diagnosed with a learning disability. She has a masterful grasp of the spoken part of the English language but her learning disability impacts her skills with written words. Because of this, her classmates and peers have noticed her struggles. She's at the age where kids are starting to distinguish themselves and others based on their differences and placing them in a hierarchy. They inevitably noticed that my youngest bio-child does not read the same way others in her class do. Once a week, she tells me about kids cruelly asking her "Are you dumb?"

Thus, the invasive questions have turned into something meant to hurt. When simple curiosity turns into a tool for control, we have to address it differently. Invasive questions that come from a place of wanting to learn aren't necessarily harmful but why is the onus placed on the subject of the question? Why do we feel we are owed answers to our invasive questions? Why do so many askers of these questions get angry when they're told the question is invasive, or that the asked doesn't feel like answering it?

My oldest came up with an amazing way to deal with unwanted invasive questions. She developed trichotillomania just over 2 years ago and has received some negative responses and invasive questions about it. She's more than willing to discuss her struggles with someone who is respectful most of the time but she has 0 tolerance for bs. When someone asks her an annoying, invasive or just unwanted question, she makes dinosaur noises at them.

Unfortunately, this is not a feasible response for adults in professional settings or polite society. There is no 100% polite or acceptable way to tell someone "That question is inappropriate" because there will always be someone who feels entitled to ask inappropriate questions and that entitlement tends to make people defensive.

We need to address the entitlement and the disempowerment with children when they are young so that they grow up knowing that there are some questions that they are not entitled to have answered. It can be incredibly difficult. Children are naturally curious and we, as parents, try to nurture that curiosity. We don't want to alienate them from that but we also want them to know they are not always entitled to getting

the answers they want.

I have tried to do my best to make sure my kids know that asking questions is ok but they need to be aware that not all their questions are wanted or necessary. They need to take responsibility for finding their own answers sometimes, they sometimes won't get answers at all. I have also tried to teach them that they don't have to answer every question that comes at them. They can choose what to share and what not to share, what to ask and what to discover on their own.

A Surprise Packet

By: Gerianne

One afternoon, I'm remembering it as around February '21, when Mary came in for the afternoon, as normal routine she had my mail in her hand. She asked if I wanted her help going through it all. I confirmed with a yes, please.

We both soon became very curious about one particular envelope. It was about card sized but also very thick. I kind of looked at Mary and said: "What the..."

Upon opening it we were even more baffled. Inside was about three or four other envelopes. Mary and I were completely mystified and soon we began a string of: "What...? What...? Who...? What..? Why...? What...?"

When we got to the included letter it said "Bet you never had two Christmas cards at the same time as an Easter card before." I started to laugh and I thought, "Who in the world..."

A woman from my church who sometimes sits in the pew ahead of me had done something I never imagined anyone doing. She had hung on to the previous years cards that she tried to send me, but those cards were returned to her because I had moved.

I was so blown away by her thoughtfulness. It really gave me immense joy to realize that someone had kept me in their thoughts and in their heart for all that time.

Remembering Dave

By: Gerianne

On the evening of August 13, '21, I was shocked and deeply saddened when I learned of the passing (July 18/21) of my friend, and DisabilityPride.net's name sake, Dave Hingsburger.

Dave and I first became friends (I'd say early in 1976) when I was in grade 9, at West Toronto Secondary High School. Dave worked as a support staff in the school for a few of us with physical disabilities. He would assist us with the mechanics of switching text books between classes (no laptops back then) taking jackets off/on, washroom

breaks, and trips up/down the elevator to get to various classes.

It wasn't too long before I preferred Dave's assistance with helping me eat my lunch over the one other staff support person, who was a very nice elderly woman, but didn't have a whole lot to talk about with a 16 year old.

One time as we were in the elevator and for whatever reason I was yammering about what a "dedicated student" I was, Dave tried to politely interrupt me, almost as if he didn't want me to hurt myself.

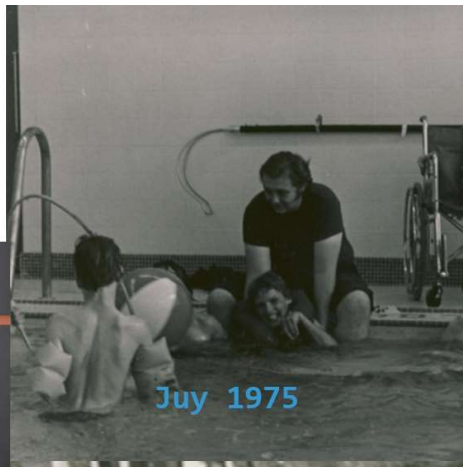
"Gerianne, do you know..." he started to ask.

I kept going: "Blah blah blah - dedicated student - blah blah blah."

Dave interrupted again, but this time with a little more umpth: "Gerianne... Do you know what the true definition of dedication is?"

"Of course I do!" I replied: "It's blah blah blah."

Dave very calmly comes back with a: "Nnnno... No. The 'true' definition of dedication is... stupidity!!!" (lol.



Metaphorical brick wall brick wall ran into - full throttle. Though he tried, he couldn't stop me from slamming face first into it.)

For many years we had lost contact, but in recent years we were able to reconnect again, thanks to Facebook. (See: "Reuniting With My Friend, Dave', under the "About D.P.net/site-history/).

Unbeknownst to me, by this time, Dave had become known globally as an advocate and lecturer on behalf of persons with intellectual disabilities. Coincidentally on the same day that Dave happened to publish an article that I wrote for his work publication, his personal blog reached 4 million hits, and trust me, my little literary contribution had nothing to do with his blog reaching that astronomical number. Actually on that day, DisabilityPride.net got its 2nd highest number of visitors ever - most came via Dave's blog and his Facebook followers.

When a few mutual associates discovered I knew Dave as a personal friend, I got a few comments such as: "You know Dave Hingsburger personally??? You"ve met him??? Like you're actually friends??? Wow! I'm in awe of you Gerianne!"

Sadly though, Dave and I had some differing views about the whole "mask wearing" issue, during the height of covid", so we really didn't connect much after that; but Dave (and Joe) will always be snuggled deeply in my heart, whether he knew it, or believed it, or not.

Sometimes I still sit here, trying to wrap my head around the concept of Dave no longer being in this world in person. It's a concept that, for me, will take much getting use to.

People who are deep in your heart don't always know they're there, but nonetheless you feel a deep loss when you realize that in this world, there'll be no more chats, no more contact, no more "I wonder how he's doing." Still, I will always cherish my friendship with him and Joe.

Thank You To Our Sponsors

We just want to say a big "THANK YOU!!!!!!" to Catherine (in Corner Brook, NL) and Barbara (in Halifax, NS) for their sponsorship of our news-zine.

A Visual Sampling of Jessica's Original Goat Milk Soaps

The League

By: Mary

In June of 2021, Gerianne was invited to be on the board of the Nova Scotia League for Equal Opportunities (The League, NSLEO) and was stood for reelection at its A.G.M. in September of 2021.

The League is a provincial "catalyst in building social, community, and political leadership of persons with disabilities within Nova Scotia. The League takes a leading role in many important community efforts and is a cross-disability voice of Nova Scotians with disabilities."

Gerianne sees this organization as one that is making a difference in advocating for a more enriched and inclusive province and she finds value in being a pat of it.

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