An Open Letter to Niantic: The Experience of a Severely Disabled Pokémon Go Player

My name is Crystal Legionaires. I'm a day one Pokémon Go player. I joined the waves of people playing in July 2016 and played for a while afterwards hunting after attending my physical therapy appointments. This is the story of a woman finding community, losing my health and what current changes to the game mean for people like me and those that will become like I am.

I have a condition called Myalgic Encephalomyeitis. It's a fairly common disease effecting between 2-8% of woman and lower percentages in men. I've dealt with it for years. It leaves me in constant pain, sometimes debilitating and very weak.

After playing infrequently I picked up Pokémon go back in October 2018. Physical activity helps my condition and the new features really drew me in. I stumbled onto cyndaquil community day by accident and ended up meeting my local raid and community groups after attending an EX raid. My health was deteriorating rapidly at my job and school and I had to drop out so Pokémon Go became my community while I attempted my best to heal.

I did raid days and would have friends drive me around and it helped me stay connected despite my physical abilities being compromised. I would do community days with friends at the local university and it helped me feel less alone. It would take me 2-4 days, weather and exertion depending, to recover from those days but it was necessary for me to have that connection.

I pushed myself in the Fall of 2019 and once again paid the price. Through sheer luck I was able to do Piplup community day before getting horrifically Ill that lasted over a month and still meant I could barely think straight by rhydon community day. One of the hallmarks of my condition is post-exertional malaise. In short, you push yourself too far your body gets horrifically sick for weeks or months. I had pushed myself to the point my body suffered a metabolic collapse trying to keep up with working and necessary life things I was doing.

In that collapse or "crash", I could barely move. I became so light and sound sensitive I couldn't play or even watch videos. It took me days to get back to be able to even look at Pokémon GO and nearly 2 months of recovering to get back to my previous baseline.

All this time the community I had built was inaccessible. I'd walk campus a bit before getting extremely fatigued and have to call it quits. I was alone and would be alone most of the time because the game wasn't built for me. In my darkest hour my community that I had built could send food and well wishes but I was physically utterly cut off from them.

Then the pandemic happened. The last thing I did was a raid train for darkrai where I got uncharistic luck. Remote raid passes were soon added but without the invite system. I locked down. Im immunocompromised I needed to be safe.

My physical health kept recovering and by the Egg event in April I was able to push myself physically to walk around 10k in a 5 hour period and hatched a shiny riolu. I started doing 25

battles in GBL a day to pass time and farm legendaries that were inaccessible otherwise but it was effective. I was optimistic things were looking better.

But all good things have to come to an end. My isolation started taking a toll on me. Being disabled meant pretending everything was fine wasn't an option. Fearing getting sick and being alone led to stress and emotional wear and tear on my body and I started once again becoming weaker.

I fought it. I didn't want to accept it. And spotlight hour being added the day before raid hour didn't do me any favors, as I didn't have a recovery day. I started deteriorating rapidly and was desperate to maintain my health, angry that my energy was so limited. My last time outside I pushed myself doing Reshiram raid hour to remote in where people were driving around.

Little did I know that would be the last time that I would walk freely again for years.

The lack of community and isolation didn't just take a toll on me, it also took a toll on my friends. My friend Kestin was an alcoholic and between that and a heart defect ended up dying the day after. He was also suffering, a liver transplant recipient forced inside. I talked to him about invites to remote raids coming soon and he was excited. He and I were both isolated and mentally destroyed. The day he died was the last day I was a somewhat capable person almost 2 years ago.

My body once again crashed but this time so much worse than previously. Walking across the room left me breathless for 30 seconds, my strength gone, my light and sound sensitivity at maximum. I cannot adequately explain what it is like to be like this. I became a walking corpse, unable to talk care of myself, a shower the impossible climb to Mount Everest, boiling water running a marathon. Too much exertion can easily lead to cycles of crashing requiring more and more time to recover and I tried my best to do so

I lost my community again so weak I could do nothing but stare at the ceiling. I tried to rest and recover but it was too much mentally by myself. After attempting to take my life for the second time in a month, I decided I had to receive help.

I went to live with some people that offered help. I started doing better and even returned to watching videos again. I could play Pokémon thanks for the pandemic incense bonuses from the luxury of suburban guest room. I believed I could get out and see my community and life again.

However that was not to be. I crashed again and made myself worse and became for all intents and purposes blind and nearly deaf. I would suffer considerable hardship trying to recover and I did make mental adjustments necessary and physical remedies I could but it came at the expense of losing a near totality of my muscle mass.

I became so weak that getting out of a bath and getting dressed became a 50 step task with 50 30 second breaks required. I was physically barely alive but determined to get better.

Pokémon go became an essential part of my recovery. It gave me something to look forward to every day. Incense meant I could meaningfully participate in events and remote raiding meant I could feel a worthwhile member of the community. After rectifying an eye issue I became able to participate in remote raiding starting with the legendary birds in fall 2020. I couldn't look at the screen long and sound was too much, but with sunglasses I could look just long enough to organize the raids and set my optimal teams.

I found my raid group at this time and we've done well over 500 raids to date with them so far. Despite being stuck and weak and unable to move hardly at all for fear of crashing, I became an important person in my community spreading news and helping with raids as people needed.

By Charmander community day I was able to look at the phone screen nearly the entire time and assist in helping run an account for a friends child. I couldn't spin stops or go to gyms or walk around and see Pokémon, but what I did have kept me going at the weakest I've ever been.

I was a mainstay or my local community willing to help out and chasing elusive raid shinies. It helped take my mind off how mindnumbingly dull recovery can be and how frustrated I could be that most of my basic life had been stolen from me. Through tears and trials I knew that I could help others in a meaningful way and search for little shiny pockets of dopamine.

I became well enough in august 2021 that I could take care of myself more or less and returned to more independent living. Then the rollback of stop distance happened. I was angry. The game that had helped me so much and that I had helped in growing and assisting others said I wasn't important. And I was lucky. I had a stop by my apartment just out of reach from inside. I couldn't reach it in its new state and even the 200 yards to the stop was prohibitive.

Then the reversion happened and I helped other players once again with raids, bringing my best to the table and determined to help as much as I reasonably could.

I had some ups and downs. I crashed several more times and ended up once again staring at the ceiling for the majority of October and November. I played as I could but once again I was reminded how cut off I was. My community were instrumental to giving me support that I needed to get through and without things as simple as invites to raids, I don't know where I'd be right now.

December brought the announcement of an incense nerf and most of us imagined the 90 second spawn rate of October 2020. I knew without a reasonable rate I couldn't play. My OSM data is based off cell data during the March/April 2020 pandemic and drastically increased my apartment spawns. But it's still around only 20 an hour. It's not feasible as a sole source for community days. And as I've said going out is no longer feasible.

The sound alone from talking and being around people levels me in a few hours. If I use my phone at the same time, that time drops to at my best now 20-30 minutes. So no matter how much I want to go outside, no matter how much I want to play how I used to I just….can't. I risk doing more long term damage to my body and getting even sicker. I'm stuck in my apartment until I'm strong enough to feasibly leave and I have no idea when that is going to be the case.

The next few months were fun but followed with the incense nerf to 5 minutes. Ever since then despite being a level 50 (as of February) day 1 player, I can't really play. I was excited to hit 50 and see the new things the game offered and then the wind were stripped out of my sails. Every community day, every event since, I can log on and get a few spawns but that's it. I'm not excited to play the game I'm frustrated and my community feels the same. I don't raid hardly at all and I feel little incentive to do that or play GBL. I'm less reliant on this community now but it hurts just watching what was a fulfilling and important part of my recovery pretend like I don't exist.

Michael, the rest of the Niantic team, this is wrecking a beautiful avenue and community and game for people that have little else. You know my condition? It's has many of the same symptoms, including the discussed above condition Post Exertional Maliase, to a condition you get from Covid called Long Covid. More and more players and people are becoming disabled permanently and unable to play. There's no incentives or nerfing that can get us out. People pushing themselves to do so risk doing permanent damage to their bodies in the process.

Around 10% of Covid cases result in long Covid and without proper guidance, many of these people will become bedridden like I am still. As Covid continues to ravage the world and especially the US, our communities that can play the game "as intended" is shrinking and rapidly.

The anger towards Niantic is real and justified. We know this game can include us. We know that the game community can be part of our community. We've experienced for the first time feeling like we aren't the invisible shadows that people pretend don't exist. And you all are taking that away from us.

Covid cases are rising and it's not safe for me to be around tons of people even if I was healthy to walk around. And pushing local meetups at such a time is going to disable people for life and then remove them from their communities.

There is little more that me and every housebound and bedbound player wants than to walk around and pretend it's the good old days but we can't.

We've been important members to support and grow your game and the communities around it, will you return the favor by making your game in such a way that we can be apart of it.

Disabled people deserve to play Pokémon GO too.

Don’t forget us

Crystal Legionaires, Day 1 level 50 player