

Stepping out of the Blue – (Bear with me for a moment, this will all make sense in the end)

Where it all began: I located a new campaign for awareness that NORD started, The 7000 Mile Rare Movement. I discovered this about a month ago and volleyed back and forth in my mind whether or not I'd get involved, with some prompting I took a chance, created an online campaign and sent an email off to NORD and asked how I could help more and, also, that I was interested in working with their Running 4 Rare teams. (That is a story for another day). I was a PKU adult, returned to treatment, pageant Queen and Advocate.

On Friday Jan. 26th, 2018, I had a 30 min. phone call with Ross (who has the most pleasant to-die-for English accent), and within that short time he asked if I would be willing to share my story & my PKU life with the public and become one of their National spokespersons for the 7000 Mile Rare Movement. I took myself by surprise that without a minute pause I said "yes." Now, this may not seem like a huge leap for many, but a decision like this would've a few years ago or even one year ago taken much soul searching and contemplation, heck 6 years ago I could hardly form my thoughts into words and make them come out. This, however, is what 2017 and my fight to regain control of my PKU life had been leading me up to. How could I say no? I didn't even consult my husband before my response.

The 2018 Miss Plus America theme has been echoing in my head "The Year of Influence" along with stories upon stories of PKU patients losing their medical coverage for their treatments on a national scale. This was once mainly the blight of PKU adults but has now trickled down to children. I took up my crown to speak for the those that felt so outnumbered that they would never be heard and those numbers grow daily, not just in the US, but WORLDWIDE.

PKU is for the most part an invisible illness, we don't look any different than the person sitting next to us and we get a lot of "oh, it's just a diet. It's not THAT bad." Oh, bless your heart, you poor soul, if you only knew and how do you get people to understand. Honestly, if anyone has had the chance to see news coverage about PKU it has been mostly parents pleading for their kids, but FACT: KIDS GROW UP we don't just fall off the face of the Earth.

When I accepted this undertaking I didn't know how fast the ball when get running. Ross got me in touch with Laura by the end of Friday and by like Monday I got an email from Leah with their PR firm. We had a 45 min call and I had to explain PKU & my life in a nutshell, which is no small feat. That got me to thinking, even kinda second guessing my decision (how much do I share? who wants to hear my story?), but I adapt and overcome and press onward. By Thursday I was sending Leah my bullet points and a brief about me and my life. So, here is the snapshot of what I've been doing the last few days, where it goes from here I'm not sure, but hold on to your crowns my Kings & Queens life is about to get interesting for PKU & this

Here is a brief excerpt from what I shared with Leah about my PKU, my life, the pageant and my purpose:

“About 6 years ago was my rock bottom PKU wise. We learned my father-in-law had ALS. The rock that my husband was so swept out from under me. I could no longer maintain the appearance of normalcy. I had a severe stutter, I could hardly walk, stairs were a no, I had words trapped that wouldn’t come out. I ended up in the hospital, neuro unit, where he was told, your wife will never be the same, she is mildly mentally impaired (and getting worse) she shouldn’t drive, won’t be able to work. She will most likely get worse and at some point she will need a group home or institution. The damage is done & is not going to get better. Then I learned of the Peg-Pal trials, which I have now been a part of for almost 4 years.

Throughout this time I would read stories and connect with PKU adults and families over Facebook. All these had 1 main overtone, they were all discouraged, felt ignored, forced into the shadows (PKU adults especially felt this way), and forgotten. Cursed is a word that many touched by PKU use. Oh, the power that word has when you speak into existence. I knew that feeling and that power. We knew I had to do something, connect with these people, give them a voice. Not just one that was roses and rainbows, but the reality.

We didn’t know the path that mission would take, but we were all in. I have been blessed to have been at the point of no return, in fact some doctors believe, my return is nothing short of a miracle because the damage my brain had was too extensive to self repair with treatment within my lifetime, but here I am. I have been given a 2nd chance many are not awarded and that many before me should have been.

My PKU has given me a purpose and mission. A strength many cannot not understand or explain. PKU has given me the ability to understand those that feel they don’t have a voice or that voice is locked in their heads rattling to break free, I connect with these people. I’ve been there and done that. I happened upon MPA about 4 years ago and took 2 years of building courage to apply. I did not go with the idea I would win anything, I went because I, like many PKU patients my age, was told you are too overweight to be “beautiful”, I was told your panic will get the best of you, why try. I was told I was flawed and society will never understand and you won’t belong. My life has been a series of you won’t and you can’t, yea I have. 2017, was my feet onto the stage, feel the waters, understand what Miss Plus America was; In my eyes if I could just make it through that week (my birthday week) I could make it anywhere & do anything I set my mind to do, that was what I went there for, I did not have delusions I would win (I had no coaching, no training, no pageant experience and I was panicked and scared) But what I found was phenomenal; acceptance, encouragement, and



more strength in my voice and mission. My sister queens encouraged me to continue my fight, and they, too would come along and help where they could. So, in reflection, I won even though I didn't." 2018, was my year to show the world who I was & that I was a fighter & survivor, again, I did not bring home a "big crown" but I brought home more, the knowledge that I am being watched, followed, and encouraged to continue my journey. 2019 I'm coming for you ☐

How does this apply to MNEA? None of this journey or life I am now leading could have been accomplished without Medical Nutrition goods like my Build 10 formula manufactured by Cambrooke; which, btw, costs my husband & I \$790 every month out of pocket because we cannot find an insurance company to cover both my Palynziq (formerly called Peg-Pal) and my much needed formula. See, no two PKU patients are alike, you will find stories of other Palynziq users that seem like a miracle "happy ending" they eat a regular diet and are healthy. Me, not so much, go back to 6 - 4 years ago in my story; remember that??? I have a very severe variant of PKU, (no matter how hard I tried as a child, teen or adult I never had in range PHE levels without this proper combination of treatment I have now come to love) I will never have a "normal" diet. I will always need my Palynziq, my PKU supplement, low protein foods, and a modified diet to maintain the amount of "normalcy" I have fought for all these years. I have requested year after year for help from the State of Kansas. We have a sliding scale here that would help alleviate my "medical expenses" (i.e. formula, dr. appts and labs) by a mere 20%, not much, but at this point any little bit helps, right? Wrong because I must seek my treatment "outside the borders of Kansas" & "you are over 18 with no natural children to care for" I have been denied even this small amount of assistance.

Does this seem right to anyone? The Medical Nutrition Equity Act would change this. This, my friends, is what we call a "game changer" for so many weary families and patients.