

# Paula McGinnis



I'm Paula McGinnis and as someone with MG and Asthma, I am well aware of the difficulties that so many are having with insurance company denials. Members of the MG community are receiving denials from their insurance for treatment not only of their MG, but other autoimmune diseases that they have. I would like to share my story with you in the hopes that I might encourage others going through the never ending denials from insurance. It was when I almost went into an MG crisis and insurance would not approve a medication that I decided to become an advocate in our region. Even though my body was weak, my mind was very strong. I began raising awareness, participation, and donations. My goal was to have a National Walk in the region of southern IL (southern IL, western KY, northwest TN, MO, and southwest IN). We now have the Southern Illinois MG Walk taking place in Metropolis, IL (home of Superman or at least his statue!). I was very honored in 2015 to represent our region as the MG hero, even though I had not stepped out of my comfort zone for heroic reasons. It has and will continue to be my goal to help all of us that walk in the shoes of Myasthenia, and to help the MGFA, who helps all of us across our nation.

Just as I will not allow MG to stop me I will not allow a denial from an insurance company to get me down either. Sometimes my perseverance is my best motivation helping me advocate about issues that will affect my MG. I have found that a lot of physicians are overwhelmed with the changes in our healthcare system and just go along with whatever the insurance company requires rather than to battle them. Often they will go through the appeal process, and still receive a denial. I have not allowed this to stop me from carrying the process further. I guess part of it is because I was an RN for many years. That has been the most difficult thing for me to overcome -- being on the other side of the healthcare system.

Just letting those that have received a denial for medication or treatment from insurance know that it is sometimes possible that insurance companies may also reverse their decision, is very important. When my insurance changed 4 years ago the new insurance did not want to pay for the IVIG treatment that I had been getting since 2008. I continued to receive the IVIG, but I also fought the fight to get it approved. I did have to finally file a complaint with Medicare

against my insurance company at which time they started a case and reversed the decision. It took 6 months for the process for IVIG, but it was finally approved. In another instance, when my neurologist ordered Cellcept in 2014, the insurance company denied it even with the physician's appeal, so I took it to the next level of federal appeal. They still denied even in federal appeal. When I ordered my Alvesco inhaler in December 2015 the insurance denied that as well. I have been on the Alvesco for my asthma since 2010, and then they said I would need to go through a step therapy and fail prior to the approval of the Alvesco that had been helping control my Asthma for several years. I am well aware of the risk involved for patients with autoimmune problems in having to go through this step therapy. It took 3 years for the pulmonologist to finally get my Asthma controlled with the added Alvesco. If my Asthma is not controlled then my MG takes a drastic downhill slide.

I decided to be my own advocate once again in the battle of the appeal process against the insurance, because no one walks in my shoes, as I do not walk in theirs. I wrote my appeal letter and sent the documentation of physician notes from the medications that I had already tried and failed. I received a letter that the appeal had been reversed and they did give an authorization for the Alvesco.

I continue to stay confident in being my own advocate whenever needed and a voice of advocacy for MG and the MGFA in our region. I look forward to reaching the MG Community in 5 states in our region for the 2016 Fall MG Walk.

Paula McGinnis

<http://join.mgwalk.org/paulaburnettmcginnis>