

March 4, 2024

RE: Written Testimony for SF 3532 in the Senate for the 93rd Minnesota Legislature

Dear Committee Administrator,

I am writing this letter to provide a written testimony for bill SF 3532 in the Senate for the 93rd Legislature. I am testifying as a patient and my statements are my own. I have Aplastic Anemia. It is a type of bone marrow failure which results in a very compromised immune system, low red blood cells and hemoglobin. Like many rare diseases, scientist do not know the cause of my disease and diagnosis is a process of elimination. I received an allogenic bone marrow transplant thanks to my brother, to treat my disease. During my health journey, I was fortunate enough to receive what I call my golden tickets which enabled a successful outcome in my health journey.

- My love for exercise which inevitably helped me detect something was wrong with my body well in advance of becoming sick, given my compromised immune system.
- My brother was a 100% match and agreed to be my donor.
- The care from world renown physicians right here in the state of Minnesota that have researched my disease and are well informed of the various chemo pre-treatments to minimize adverse outcomes.
- My choice to be a clinical laboratory scientist and obtain an undergraduate degree in Medical Technology where I studied the field of hematology.

These golden tickets were critical in me receiving my diagnosis, treatment and most notably achieving maximum coverage from my healthcare insurance. During the course of diagnosis and treatment, I navigated multiple prior authorizations denials and subsequent appeals. All of which I am happy to report were successful. However, it doesn't feel like success to me. This process opened my eyes to the brokenness of the prior authorization process. I learned of the very real burdens it puts on our already constrained and burned-out clinician resources as well as patients and their families.

During the prior authorizations I needed for my treatment I received several denials. This required my doctors to appeal the decision to obtain coverage. My doctors could only help me in my first round of appeals. They were not able to extend resources into the second and third round of appeals with my insurance provider. At this point, I needed to take matters into my own hands.

My most challenging claim was to obtain coverage for my genetic testing, which led to three rounds of appeals. This was testing my physicians waited to receive the results of before they would move forward with my transplant. Given the severity of my disease I moved forward with the testing, despite the initial denial from my insurance.

What did this mean for me? I spent countless hours searching and reading scientific literature as well as understanding the specific appeal process of my insurance provider and subsequently writing appeal letters. This included many phone calls with my insurance provider discussing my options and providing evidence as to why my testing was indeed medically necessary. Ultimately, I was successful in the third round of appeals to receive coverage for the genetic testing my doctor order. To be clear, this is the same testing that my doctors waited to get the results from before moving forward with my transplant as

they wanted to confirm the best chemo pre-treatment regime as well as rule out any potential genetic factors in my diagnosis as my brother was my donor. There is nothing about the prior authorization process that served to improve my care or alter my treatment course of action. In fact, the process opposed the scientific evidence without adequate justification or merit. The process simply delayed my treatment, used precious clinician resources, and most importantly had a negative effect on me as a patient.

The multiple rounds of appeals and level of scientific evidence I personally had to obtain and provide as a patient to ultimately prove medical necessity for testing ordered by my doctor added a significant level of burden and stress on me. In fact, I attribute my education and field of study as the reason why I even entertained pursuing the second and third rounds of appeals. To give you some perspective as to the extent of the information I provided to receive coverage, I am enclosing a redacted copy of my third and final appeal letter which was successful in obtaining coverage.

Many patients in similar health journey situations are not able to access or even understand the information needed to be successful in an appeal process. While I can understand the reasons why a prior authorization process may exist, the current process is not efficient, lacks adequate justification and certainly is far from equitable. We need a much more transparent and efficient process which improves the rate of inappropriate care denials that are at the expense of disenfranchised patients.

Thank you for considering my lived experience in your deliberations.

Regards,

A handwritten signature in cursive script that reads "Dawn Stenstrom".

Dawn Stenstrom

Enclosure: Redacted Appeal Letters