February 2019

Joint Budget Hearing Testimony of Demetra Efstathiou-DeFeo

A month after I was born in October of 1985; my parents received a letter from the Department of Health, stating their child had been diagnosed with sickle cell disease. My parents, in disbelief, were then tested for sickle cell traits. Unbeknownst to them, both were sickle cell trait carriers. After months of screening living relatives, it turned out that my maternal grandfather was a carrier. My paternal grandmother had at least the trait lived in Greece and died of breast cancer.

It is my goal to educate those who believe that sickle cell disease only affects African-Americans. Even within the medical field there is misconception about who can be affected by the disease. I am asked how I got sickle cell, when I was diagnosed, and if I'm sure it's a diagnosis of sickle cell disease.

I am a Caucasian woman of Greek descent born in the Bronx New York.

The disease has affected me since birth. I was under the care of a Greek hematologist oncologist who was very knowledgeable in the disease. She put me on a daily regimen of prophylactic meds including folic acid that limited my hospitalizations to once or twice a year for pneumonia, lung infections, acute chest syndrome, and sickle cell crises, often requiring blood transfusions. My parents educated me on the disease as much as they could and the importance of correct dietary supplements, nutrition, vitamins and water intake, and how to read my body at first signs of pain and weakness. Hospitalizations caused me to miss weeks of school at a time in elementary and high school and beyond. I had many physical limitations when it came to extracurricular activities, family vacations, and social activities. I was bullied for being significantly smaller, thinner, and shorter, than other girls. At 13 years old, my growth plateaued and an endocrinologist recommended growth hormone which I took daily by injections for two years. My parents health Insurance covered this medication and I was able to gain almost 10 inches and reach my current height.

The limitations of this disease are too many to articulate and difficult to prove. It's not easy to explain how a last-minute migraine, weakness, pain, sickness, or the weather might stop me from coming out of the house. It's not easy to explain why I have been forced to miss long periods of work or school.

It's not easy explaining the pain when I'm not showing any physical signs, and people often fail to understand how this limits me, and why I go through periods of depression, and have a constant anxiety. I'm constantly worried about pain striking and missing out on life.

As educated as I had become about my disease, I still acted out and made destructive decisions in my 20's, which affected my relationships and my health. For a while I believed that I had no reason to take better care of myself, and no reason to care about my future. It was at this time I tried to live on my own, and applied for and received Medicaid. Medicaid paid for

everything At the time, I would receive bill statements and be surprised at how much was covered.

As I gained my degree and employment and moved to upper Westchester New York, I was informed I could no longer carry/renew Medicaid and made too much money. Others may have a better chance of qualifying for Medicaid and disability than me, because of my socioeconomic status.

I have been lucky to have educated parents and support from family and the awareness to seek out the best specialists and travel to get answers, but others may not be so lucky.

Through the persistence of my supportive family, my psychologist, antidepressants and my husband, I gained a positive outlook on life. I studied social work with the hope of learning about health care and contributing to the mental health care field.

Thankful to my parents, I studied at Fordham University and I have become a Licensed Master of Social Work. I found a job that offered health insurance when I aged out of my parents insurance policy. I find it difficult to remain employed in my field. I also find it difficult to work enough hours in order to receive health benefits. Doctors have told me that full-time work is not an option, and I fear living with a pre existing condition, medical bills and medical expenses with little income. The social work jobs required field work that was strenuous and required activities straining my body physically including, carrying heavy bags of toys, walking up flights of stairs in inner city buildings, driving a community school bus, traveling on field trips, causing at least back problems, nerve spasms and bulging discs.

Currently I am not working and I am unable to maintain a full time career in the field to which I have devoted so much time. During these times I was denied disability and was unaware of any other program that could potentially help me with my health costs. I began to pay thousands out of pocket, almost making my paycheck to pay for my healthcare.

My most recent social work employment for a local non profit community youth council, involved teaching elementary middle school and high school students how to make better decisions inside and outside of school, especially educating them on the dangers of opioids and addiction. This was a great and important deal to me, as I have taken more opioids than I ever wanted to and still continue to rely on them in times to save my life or to limit pain to a tolerable amount. It is not difficult for me to request a refill on a pain medicine such as oxycodone, or to receive care in the emergency room, however when more simple codeine and morphine doesn't work to relieve pain anymore I don't feel comfortable about that. Additionally the side effects of these pain medications have frightening side effects on my organs and skin among other things.

I now reside in Northern Westchester where there is no sickle cell program and no support in any of the surrounding hospitals! I continue to travel to the Bronx even in times of emergency to find care at Montefiore Medical Center. The care I received in Westchester County was subpar, hematologists hadn't been specializing in sickle cell and I had my worst hospitalization experience that lasted over 30 days crippling my arms and legs with sickle pains. I contracted a blood antibody in one of the blood transfusions I received there, now putting a limit on what

blood I can accept in the future. Needless to say Westchester is in need of hematology specialists, nurses, social workers and programs to support sickle cell disease patients, not just other blood cancers.

After over 30 serious sickle cell crises, over 200 units of blood, opioid and pain medication and 10 years of oral chemotherapy medication Hydroxyurea, I feared being able to come off of these medications to be able to safely conceive and have a healthy child and breastfeed and rear that child.
I married in 2015 and decided trying to conceive after thorough testing of my husbands blood as well. In 2018 I did come off of the medication, under the care of head of sickle cell in the Montefiore hospital in the Bronx, I did conceive and after three months without hydroxyurea, a multitude of genetic testing chorionic villai sampling and an amniocentesis I carried out a healthy pregnancy to 37 weeks. My daughter was born in an emergency c section situation with blood transfusions before, during, and after the surgery.
I survived, but I suffered a disastrous pulmonary embolism in both lungs two days later and endured another crises. I was discharged after ten days with my baby, with hundreds of daily blood thinner lovenox syringes, with oxygen tanks, a breast pump and pamphlets on newborn information! I learned even more now that I'm a very strong woman and continued to stay off medications and breast feed for five months. A post partum nurse visited my home once and never again, which was terrible for me as a new mother with a sickle cell diagnoses and a saddle PE. Maybe it is so in Westchester that sickle cell disease is barely recognized?
My anxiety is higher than ever before and I suffered two more hospitalizations requiring transfusions subsequent to the delivery and the PE in 2018. My health forced me to stop breastfeeding. My post partum depression and anxiety remains strong. I returned to a weekly psychologist which I had done in the past numerous times, I stopped at the end of 2018 because of our catastrophic family deductible going into 2019.

I try to remain conscious of my feelings and mindful of my anxiety and stress level. I am conscious of what I eat and drink, where I go, how long I'm out, the weather, how strenuous the activity may become, since all of the above adds to my symptoms. Every day I take my prescribed medication of hydroxyurea, and folic acid, and deal with its side effects, added a nightly medication of Xarelto an oral anticoagulant. And now I added a baby who is loving and cuddly and has a sickle cell trait.

I have strong pain medications that I keep in a locked box and I refrain from using daily or weekly. I am patiently waiting on the prospect of medical marijuana not only for my pain and headaches but also my anxiety and postpartum depression! It has taken over a year to get an appointment within the medical marijuana clinic in the Bronx, and I look forward to the opportunity to reduce destructive opioid use.

I'm 33 years old now, For the last 20 years I've always wondered how long my life will last, how many days will I enjoy pain free, how much will I be able to accomplish, and find my purpose. I have accepted living with a chronic illness.

I am eager to improve the awareness and prevention of the disease. Before I was pregnant I had created a website, www.sicklecellconnection.com, blog, survey, Facebook page, and Twitter feed. I participated in sickle cell walks, hospital-affiliated sickle cell communities, medical studies, and public service announcements. Each day I take time to maintain a positive outlook on the future. I'm currently planning my child's first birthday party and have my hands full with my health and staying alive and well for my husband and my daughter.

The doctors, hospital stays, tests, and many struggles made me who I am. I look forward to finding a program and support network in Westchester that may help with stigma and join forces with similar conditions such as thalassemia or Cooley's anemia. I look forward to comparing how people with the disease may be struggling in getting help with pain. People should take this illness seriously because the stigma of sickle cell disease and the population that is most affected is often overlooked and socioeconomic status continues to affect care and disease outcomes for the different populations who suffer.

I'm requesting a medical program with a supportive team of health care professionals that is home to Northern Westchester County, New York. I'm requesting to positively increase awareness within my Caucasian Greek American community and increase accessibility to healthcare, research and medication.

Sincerely,
Demetra Efstathiou DeFeo