

Testimony for Public Hearing
Public Health Committee
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Steph Sokolowski
26 Westgate St
West Hartford CT 06110
HB 6580

Chairman Ritter, Chairman Gerratana, Members of the Public Health Committee:

I am writing to ask for your support for HB6580: An Act to Create a Rare Disease Council. I am 42 years old and I have Darier's Disease which is a rare, genetic skin disease. When I was about 12 years old the doctor took a biopsy to see what the rash was, as he was not sure. I was in 8th grade and the rash was all over my face. Kids asked me if someone threw acid on me or why I didn't just get some acne medicine. I was told to cover it up with make up by mean girls. What they didn't know was makeup and certain things made it worse. I would come home and cry and have to put on Medicated creams or gels and they burned and I would scream in pain and my mom would hold me as I cried even more. They would try antibiotics and those gave me infections or bladder problems.

I have seen many doctors over the years and they all say they need to research my condition to see how best to treat it because they haven't had much experience with it. Years later one doctor even had me do another biopsy just to be sure it was Darier's Disease. One way to treat Darier's is with a pill that can cause many side effects including cancer and you have to be on two forms of birth control in order to even take it (I opted against it). I have tried many special soaks, cream, ointments, expensive shampoo and soaps, gels and antibiotics and they will help a little but not clear it up. Basically they will keep a flare up at bay at best. Recently I had a very bad cracked thumbnail from the rash. I developed a Staph infection and it took a very long time to heal and the nail is still very damaged.

Currently I have the rash around my neck in almost a band. It can keep me awake at night. The rash stings and burns, cracks, oozes, bleed. It feels very tight. I feel so ugly and self conscious. Even as an adult people say very cruel things.

"What happened to your face"
"OH THATS SO GROSS!!"

Kids have pointed at me and said ouch, you have a booboo. Some people I know and others are complete strangers. The rash moves around. It can be in a lot of spots or like now it is concentrating around my neck. I have a few areas near my inner thighs and on the sides of my torso but nothing compares to my neck at this time.

Dealing with a rare disease that doctors do not understand and others can not relate to is extremely hard. I can't always afford the medications they want me to try. If I do, they are very expensive and don't always work or make my rash even worse. Plus when I am sent to a specialist my insurance charges me more. I have to wait MONTHS to see them and sometime the flare up has calmed down so they send me away saying come back again when it happens.

I would love for my care to be more affordable and to get treatment that works and won't hurt me more and to not have to explain this rash all the time. People use to worry I was contagious. The revolving costs can be overwhelming. If someone could focus on Darier's disease and get real answers and not make it worse or just "better" for little awhile I would be so ever grateful! I believe the development of Rare Disease Council in Connecticut could be extremely helpful to myself and other adults suffering from their own rare disease.

Thank you for your time and consideration.
Sent from my iPhone