

7-13-2020

Dear Medical Department,

My son, Samuel Warren Shaffer, has had two congenital conditions his whole life. They are Central Core Myopathy and Marfan Syndrome. Samuel asked me to document this to you for the purpose of allowing him to occupy a lower bunk while in the Central Utah Correctional Facility in Gunnison, Utah.

Samuel had all of his medical history with him when he was arrested and those effects are being held in evidence in Cedar City, Utah. However, I was able to find in my papers at home a physical form that was filled out when he was living in East Carbon, Utah in 1996. We were getting ready to move to Florida and I asked for a physical for him to take with us for his new school system.

The form states that he has Central Core Myopathy and Marfan Syndrome. He was diagnosed with Central Core Myopathy in Sacramento, California by a Dr. Ford at the UC Davis Children's Hospital after they performed a muscle biopsy. Dr. Ford said that 95% of his muscles were affected. We were aware of Samuel's muscle weakness since he was about a year old. He did not learn to walk until he was 18 months old and walked with an unusual gait like a toddler until he was about 6 years old. His gait improved but he has had continued muscle weakness in his arms and legs his whole life. He has difficulty walking upstairs unless he has a handrail to pull up on. He cannot go from the floor to standing unless he has something to pull up with or uses the "Gower Maneuver" pushing against his legs to help himself up. This is why it would be helpful for him to be on the bottom bunk so he does not have to climb to get into bed.

If you will watch Samuel walk you will see that he swings his leg forward to use his upper thigh to throw his leg forward. This is especially pronounced if you watch him try to run. Or you can ask him to sit on the floor and then get up. You could ask him to squeeze your hand or open a heavy door to see his arm weakness.

Samuel has done what he can to mask these problems in the prison system so as to not appear weak or set himself up as a victim. When others have noticed any awkwardness, Samuel has brushed it away with excuses in the past. This is why I was surprised that he asked me to contact you with proof of his disability. This is the first time since he has been in prison that he has been assigned a bottom bunk. He says it is so nice to not have to work to get up to a higher bunk and so when he saw there was a chance to make this permanent, he asked for my help. I assume that he would want this information to remain confidential. Samuel does not usually ask for favors or consideration. It is his way to "make do" in whatever situation he is in.

I am enclosing information on Central Core Myopathy. It is considered a "rare" disorder so you may not have had much experience with it before. I am willing to answer any questions you may have. I respectfully request that Samuel be allowed to have a lower bunk if one is available. Thank you for all that you do for the inmates in ensuring their good health.

Sincerely,


Mary C Young