

April 14, 2013

Dear Medicaid Therapeutic Committee,

We are writing this letter because last year we had a baby who was diagnosed with Prader-Willi Syndrome and we feel strongly that he should be provided with growth hormone therapy through Medicaid. Prader-Willi Syndrome is a rare chromosomal syndrome that causes severe hypotonia and failure to thrive in infancy and later an unrelenting desire to eat beginning around the age of two that lasts for the rest of life, as well as many other complications. Zander was diagnosed with this disorder when he was six weeks old. At that time, we did a lot of reading about Prader-Willi Syndrome and were devastated by what it meant for our son. We knew that Zander's life was going to be very difficult both for him and for us. Zander came home after nine weeks in the NICU. He was on oxygen continuously, had his tongue stitched to his lip to keep it out of his airway, was fed with a feeding tube, and needed constant monitoring. Zander was lethargic and slept the majority of the time. We had an occupational therapist come to our home once a week to show us techniques to help Zander get stronger and learn to eat on his own. After doing these therapies day after day with little or no improvement, we began to feel very discouraged.

After doing some research and talking to other families with PWS children, we discovered that there was a medicine that could improve Zander's quality of life - growth hormone therapy. We read studies that showed what growth hormone therapy could do for Zander - studies show that growth hormone can increase height and hand and feet sizes, decrease body fat and body mass index, increase muscle mass, improve respiratory function and physical performance, and even improve certain cognitive skills. At this early age, meeting developmental milestones is critical and can set the stage for the rest of his life. Right away, we began our battle to get Zander the medicine that could change his life for the better. Unfortunately, it's very expensive medicine and has proven to be very hard to get for Zander. Finally at five months of age we were able to give Zander his first injection (We were able to receive growth hormone at no cost from Nordicare). We started to see a difference in Zander after just a few weeks. After just three weeks, we were able to decrease his oxygen from $\frac{1}{4}$ liter to $\frac{1}{8}$ liter. A couple weeks after that, we decreased it again from $\frac{1}{8}$ liter to $\frac{1}{16}$ liter and finally to no oxygen at all during the day and very little at night after about two months on growth hormone. A few weeks after beginning growth hormone, Zander also began to suck on a pacifier for the first time. He also began to show interest in toys and reach for them. A few weeks after that he was grasping toys and pulling them toward his mouth. He also started to

vocalize for the first time in his life – he started to cry when he was unhappy for the first time and then laughed a couple weeks later. After about two months of growth hormone, Zander started to hold his head up and gained some trunk control. Zander has been on growth hormone therapy for four months now and is trying to sit up on his own as well as attempting to roll. He sleeps a normal amount, shows more interest in the world around him, and is a lot more active than he was before the growth hormone. Now when we do the exercises the therapists show us, we see a difference and are so much more optimistic about his future.

We are writing this letter because Idaho's criteria for determining approval of growth hormone are outdated and invalid. Zander is not able to receive the growth hormone he so badly needs from Medicaid at this time solely because he is not short enough. Fortunately, we are able to get it from the pharmaceutical company for free for now. In the last decade there has been so much more research on the benefits of growth hormone for more than just linear growth. Medicaid should provide growth hormone to all children with Prader-Willi Syndrome as soon as they are diagnosed, whether or not they are below a certain percentile for height. This medicine can change their lives. Our geneticist at Primary Children's Hospital told us that growth hormone is changing the phenotype of Prader-Willi Syndrome. Without growth hormone, Zander's would be faced with a future of morbid obesity, low muscle tone, lethargy and an almost certain shorter life span due to complications from obesity such as heart disease, diabetes, respiratory failure and heart failure. We want our son to have a brighter future and we believe that growth hormone will play a huge role in that. Please consider changing the criteria for growth hormone in Idaho and change the future of children like Zander.

Sincerely,

Rena and Steve Broderick

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Freedom
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