

August 3, 2016

T.J. Pulliam, MD, Chair

Long Term Care Committee

c/o Ms. Paige Bennet, Assistant Chief

Healthcare Planning

Division of Health Service Regulation

2704 Mail Service Center

Raleigh, North Carolina 27699-2704

RE: This letter is in support of an adjusted need determination to be included in the 2017 *State Medical Facilities Plan* (SMFP) for a new dialysis facility in Graham County, North Carolina

I am writing this letter to express support for the adjusted need determination proposed to be included in the 2017 *State Medical Facilities Plan* (SMFP) for a new dialysis facility in Graham County.

I feel the need to share my family's personal story in dealing with the obstacles involved with being on dialysis in Graham County. To begin I will share that I was raised to believe in hard work and a can do attitude. We believe that you work for what you have and you do not take handouts. I grew up in a large family, Mom and Dad (both diabetics) four brothers (all diabetics), a sister and myself. My father was diagnosed with diabetes sometime in his late 40's along with that came heart disease and heart attack, which caused him to have to have open heart surgery. At that point I saw my father change, he no longer was the man who worked hard each day doing physical work that he had done his entire life. He had been a logger for most of his teen years and a big part of his adult life. At that time he was operating a dozer and was running the county sanitation (garbage dump) site. He had to quit he did not have the health it took to do that type of work anymore he had to retire. Not long after that time we discovered that he had kidney failure and he was given the choice of dialysis or not. He did not want to burden our family by having to travel for this dialysis and really at that point we did not know much about dialysis and what all was involved with it. I know that if there had been a center in Robbinsville he would have chosen to do dialysis at that center, but there was not one here so my dad decided to go on a peritoneal dialysis to be done at home. My mother and my

older sister Pam were both trained in this process, and for the next few years my mother quit her job to take care of my father. Mom would do the dialysis every four hours getting up in the middle of the night and being right by his side the whole time. We helped do what we could but as a teenager I cannot tell you how difficult it was to watch this strong hard working man go through what he did with the at home peritoneal dialysis. Not to mention to watch my mother become a caretaker who bore the responsibility of my dad's life or death every four hours because she knew if she was late or did not wake up and get the dialysis done it could cause her husband to become very sick or ultimately die. Dad and Mom did not really have a quality of life for the next few years, dad's health declined there was countless hospital stays and he became bedridden for the best part of the last year of his life. He suffered a couple of strokes and ultimately we called for the ambulance to take him to the hospital (the closest hospital that is equipped to care for a dialysis patient is 100 miles away in Asheville) where he was admitted on New Year's eve 1999 and he passed away ultimately he was overloaded and the fluid went into his lungs he died later that night. My mother was exhausted but in a few months she found a job with the county government as a custodian and went back to work.

During the time my dad was sick we found out that my two oldest brothers were diabetic also. Marty (the eldest) worked in a local furniture factory and was a cabinet builder on the side. Mike worked construction jobs on ride-away and at this time was working in Atlanta on a rock crusher. Mike became too sick to work out of town and quit his job and came home around the time of dad's death and worked as a mechanic here in Robbinsville for the next two years. He was diagnosed with kidney failure and put on dialysis around 2001. Mike having watched how my dad did with the home peritoneal dialysis chose to do hemo dialysis and he went to Sylva DaVita center for a little over a year. Mike traveled on the transit van back and forth on Tuesday Thursday and myself or one of my brothers or sister would take him to his treatment on Saturdays. Mike stayed nauseated and weak during his time on dialysis and most days he was so tired he really did not have the energy for anything else besides his long trips to dialysis. After a little over a year and an open heart surgery to get him ready for a kidney transplant. Mike was put on a transplant list. He was fairly young in his late 30's so he was considered a good candidate. We witnessed nothing less than one of God's miracles. After two months of being on the transplant list Mike got the call that he was second in line for a possible match for a kidney. We went straight to Charlotte and the next day Mike was in surgery getting his transplant, we were overjoyed, scared, and so grateful that he would no longer have to endure the pain of those needles, the exhaustion, not to mention the long trips back and forth three days a week, sometimes in the snow and ice just to stay alive. The transplant worked and we knew that his long trips back and forth for now were a thing of the past for a while.

In 2010 my oldest brother Marty got sick and we found out that he too was in kidney failure, Marty went on dialysis later that year and chose to go to the Cherokee center because it is a little closer than the one in Sylva that Mike had gone to. Marty however was too sick to be considered a good transplant candidate and stayed on Dialysis for two years. In that time he got an infection in his leg and had to have an amputation. Marty was in a wheel chair for the

last year and a half of his life. He also had lost most of his sight to the diabetes in spite of the laser treatments and everything the doctors done to help his eyes. Marty had dialysis 3 days a week but chose not to ride on the van back and forth. I was fortunate enough to be able to manipulate my schedule at the 911 center and take him to his treatments on Tuesdays and Thursdays and my sister Pam took him on Saturdays. Again rain or shine snow or ice Marty never missed a treatment, not a single one. His body tolerated the treatment better than Mike had, there was not as much nausea and Marty kept a pretty good appetite. However with the long trips the exhaustion was the same, at the end of the trip Marty would get in bed and have to rest just to make it through the day on treatment days. Again I believe that if we had a center closer his quality of life, as well as my fathers would have been much better. This continued for a couple of years and then as you see often with dialysis patients on the arm that has the fistula for the dialysis there is compromised blood flow to that extremity. Marty got necrosis (decaying tissue) due to lack of blood flow he had a couple of surgeries on that hand but in the end he was tired and ready for it all to end and decided to stop his dialysis treatments and let nature take its course. By the end of that week he had passed away in the same manner as my father. That was February 13th 2012.

We had found out that my youngest brother Darrin was diabetic when he was in his 30s also. Darrin also worked in construction on ride a way and he too became too sick to work off anymore, so he got a local job delivering oil for Duncan Oil Company. Darrin too went into renal failure it was in 2012 not long after Marty had passed. Darrin was heartbroken to not be able to work and provide for his family which was his number one concern. He had battled problems with his blood pressure for a few years along with the diabetes, and I watched as his health drastically declined the last year that he was alive. Darrin desperately wanted to be healthy he had a loving wife and a son Dakota who was his whole world. His happiest times were spent outdoors, either hunting or fishing. He and Dakota were always on the lookout for that perfect hunting spot or fishing hole. When telling stories of their adventures, always in vivid detail, they each would become so caught up that one would finish the other's sentence without altering the story at all. Sonya (his wife) often said that the two of them spoke a language all their own. You would rarely see one without the other. We were all in hopes that Darrin would also receive a kidney and were sure that at his young age it was a good possibility that he too would find a match. If not he faced dialysis. A fate that he had already seen our father and our brother go through and suffer a long painful deaths. As well as the year and a half that Mike had spent on dialysis and the nausea and exhaustion that comes with all the travel. So Darrin decided to try for the transplant. I was sure I would be a match so I went to get tested however during our testing I found out I was overweight and needed to lose weight to be considered as a possible donor. Also we found out that Darrin's heart was only working at 20% and he was not considered a transplant candidate because of that. He had a decision to make, he needed heart surgery but it would be complicated he sought out a couple of opinions and found a young doctor that was confident enough to do the surgery. I talked with Darrin a lot about dialysis and that was not something he wanted for himself if he did not have to.

Quality of life was important to him and Sonya, so he made the decision to try the heart surgery and get on the transplant list. We all were in high hopes that surgery would go well and soon he would be on the list. It did not turn out the way we were hoping. During Darrin's surgery they done 6 bypasses and 5 cleanouts, they worked on a total of 11 arteries. The doctor said it was the most complicated surgery he had done and it was touch and go. Darrin was never out of CCICU at mission hospital. Over the next week he would undergo a pacemaker surgery and ultimately pass on from heart failure a few days later, it was January 15th 2013 almost a year since Marty had passed. Dakota had lost his dad, best friend and number one hunting buddy at the age of 12.

Mike went for his yearly checkup for his kidney in 2014 and they told him probably within the year he would be back on dialysis. The kidney had lasted 11 years and that was within the expectant life of a transplant and it has been a good one. However we knew it would not last forever and it was time to start preparing for the possibility that Mike was going back on dialysis. By October of last year mike had his fistula surgery and is now on dialysis again. He goes to the Cherokee Dialysis center. In December he got an infection in his right foot that would not heal so he had to have a below the knee amputation. He was in a rehabilitation center for a few months and then we brought him home. A few months later the same thing happened to the other foot and he has had that leg taken off below the knee also. Mike is currently in the Graham healthcare and rehabilitation center doing therapy and hoping to get fitted with prosthetics very soon. Once again we see the can do attitude that was instilled in us at a very early age. Mike has many hurdles to cross and so many obstacles in the way of his daily life. On dialysis days I see him get back from an 8 hour day on the van and on the machine and mostly he is exhausted and doesn't have the strength to sit up and eat his supper without some rest first. I just wish that he did not have to travel so far on the van to get to his dialysis treatments. They have increased his treatments to 4 hours 4 days a week this time around and all the people on the van that only go for 3 hour treatments have to wait for him to get finished to come home so I know it makes it even harder on them as well. Again this time my sister and I make sure he gets there on Saturday's and in bad weather. I have personally had to drive in treacherous road conditions many times with both my brothers getting them back and forth to Cherokee and Sylva and I will continue to make that happen for Mike no matter what.

In closing I would like to thank you for this opportunity to give a voice to the struggle that my beloved family has endured. I do not like to share our struggles with anyone because again I am the youngest in a very proud and private family that was raised to be strong enough to handle the problems that we are faced with on our own. It just simply is not in our nature to ask for help. God does not put more on us that we can handle, but he does provide us with whatever we need to get through those struggles. It is my prayer that he will again do so and all the people who are on dialysis now and in the future will benefit by having a center within a few minutes' drive. With my family's history I am well aware of the fact that this center might one day help me, not just as a caretaker to my family but, as a dialysis patient as well.

I ask that the Division of Health Service Regulation approve the adjusted need determination.

Sincerely,

Misty Hembree

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