

**Testimony of Tracie Revis**  
**Senate Committee on Indian Affairs, Oversight Hearing on**  
**Contract Health Service**  
*June 26, 2008*

Mr. Chairman and distinguished members of the committee, my name is Tracie Revis. I am Yuchi and Muscogee Creek from Tulsa, Oklahoma. I am a second year law student at the University of Kansas and a recent cancer survivor. My entire life, starting from my birth I have received services from Indian Health Services (IHS). I am all too familiar with the process of IHS, and contract health services (CHS) and how long it takes to get services, if you are fortunate to receive them at all. I am excited to submit testimony on this matter of IHS-Contract Health Services. I am excited because I believe that stories like mine need to go on record so that perhaps something in the future will change. IHS has been a double edged sword for me. It has been the system that hurt me the most, but yet saved me at other times.

**Diagnosis**

In 2005, I graduated with my Masters degree from the University of Oklahoma and began law school at the University of Kansas. During my first semester of law school I became very fatigued and my lymph nodes became painful. I was losing weight, became very pale, and was experiencing night sweats. I went to the Haskell Indian Nations Indian Health Services clinic in Lawrence, Kansas where the doctor ordered a chest x-ray and diagnosed me with walking pneumonia. He prescribed antibiotics but my symptoms persisted. For three weeks the doctor repeated x-rays and treated my illness as walking pneumonia. There was some discussion about ordering a CT scan, however, because Oklahoma was my home area and I was in Kansas, we had difficulty getting authorization for a referral to the local Lawrence facility.

Finally, in November, a year after I started going to the doctor for my symptoms, I had become too ill and the doctor at Haskell ordered the CT Scan at Claremore Indian Hospital in Oklahoma. The doctor at Claremore did a full workup and CT Scan. He immediately reviewed the CT films and informed me that I had a large mass above my heart area and that I would need to have a biopsy immediately. His inclination was that I either had a form of cancer or a thymoma. He wanted me to meet with a thoracic surgeon to discuss the possibilities and have him review my films.

*The Referral*

My referral “for evaluation” with the thoracic surgeon “and a biopsy if necessary and any additional treatment if necessary” were sent to my tribal contract health department. However, I ran into several complications and was deferred, denied and then mysteriously approved. The process was unclear and confusing, and I was not contacted by CHS if there was missing documentation. I had to constantly call my tribe’s area clinic and the main tribal complex contract health services office to get information on my referral status. Upon receiving the approval for the biopsy I had to call and schedule the appointments myself and then coordinate with the local clinic’s caseworker. The surgeon’s office informed me that until I could confirm

payment that they could not discuss the possible dates for surgery with me. In December, a month after the mass was discovered, I went in for the biopsy.

The thoracic surgeon decided to biopsy a tissue sample from the mass instead of biopsying the lymph nodes. I was informed that that there would be a small incision below my collar bone to take the tissue sample but, if the thoracic surgeon could determine with certainty that the mass was a thymoma then he would perform a sternotomy and remove the mass. After the biopsy began the thoracic surgeon could not get a good tissue sample and consequently performed the sternotomy which ultimately removed 75% of the tumor. I was in the hospital for six days following the procedure. I became completely dependent on others to assist me.

On Christmas day, I was given the official diagnosis of Hodgkins Lymphoma. At that time there was one tumor and it was at an early stage 2 (since it was only in the chest area and not below the diaphragm).

### **Getting Treatment**

In January 2006, I was told that there were some concerns about my referral originating from Haskell Health (because it was in Kansas) and concern because I did not have a utility bill in my name within my tribal boundaries. Because of these concerns, my tribal CHS requested a verification of my residence. Again, I explained that I was a student when I was diagnosed and that upon moving back to Oklahoma I had to move back to my grandmother's residence and therefore all of the bills were in her name. During the address verification period in February, I developed a bad cough and went to Claremore IHS to see the doctor that had performed the CT scan. He ordered another chest x-ray which showed that the mass appeared to have doubled in size since pre-surgery. He inquired about my progress with getting an oncology appointment and I explained to him what I had been told by my tribal CHS that my referral was approved pending residence verification.

My doctor was very concerned and decided to call the main tribal CHS to find out when I would be able to schedule an appointment. He spoke with my caseworker at the tribe, who informed him that my referral had been denied. He inquired about the appeal process and asked if I had been notified of the denial. The caseworker responded that I had not been informed and that I would not be informed for at least 4 weeks, then I would receive a letter in the mail telling me that I had been denied. Also, that if he (as my referring physician) wanted to send another referral he would have to wait 4 weeks and then we could appeal with a new referral. He asked about why I had been told that it was "approved pending verification" and had the CHS office received Haskell's letter stating that my address on file was listed as Oklahoma. She said that it was denied because they did not have any money and then she read him the policy of denying a referral and policy about waiting 4 weeks before notifying the patient. I was in the room for the entire call which was on speakerphone.

Advocating for the urgency of treatment, my doctor inquired whether the CHS caseworker understood how important it was that I see an oncologist right away. She said she could not do anything and that I needed to speak with the local caseworker at my tribal clinic. My doctor was very upset and decided to call the tribal CHS director, unfortunately she was unreachable that

day. My doctor advised me that my health could not wait, and that I needed immediate treatment. He decided to call other cancer facilities within the state to see if they were willing to take me as an uninsured patient. Every hospital that he called said they were at their fill of uninsured patients and that they could not take me on financially. At that point my doctor suggested possibly seeking treatment out of state.

After the denial from IHS, I called the State Department of Health Services inquiring about state assistance and was told that I had the “wrong type of cancer”. I did not qualify for any assistance because I did not have children and was not disabled. It did not matter that I did not have an income. Frustrated by the system, I called state representatives, tribal officials, and anyone who knew someone that might be able to offer suggestions. I followed up with the CHS Director and was informed that I was “approved pending verification of my residency”.

Three months after my biopsy, I finally had approval for treatment and had an appointment with an oncologist. My new oncologist reviewed all of the previous medical records and ordered more tests to determine the final staging of my tumor size before I began treatment. Upon initial review he presumed my staging was stage 2 because of the location of the tumor above the diaphragm. However, because of the time it took for me to get approval to begin treatment, the tumor had grown and I now had 3 tumors in my chest and neck. Also, I had enlarged lymph nodes in the groin and in areas surrounding the aorta and an enlarged spleen and liver. My final staging was a 3(B)(E).

I tolerated the treatment well. However, because of my anemia and weight loss my oncologist recommended red and white blood cell boosters. Unfortunately, the cost of the injections was \$4,000 for one and \$6,000 for the other. My oncologist knew that CHS would not and could not afford that amount so he put me in a clinical trial. Earlier this year, the FDA released a report on one of the drugs that noted that it should not be given to young patients with chest, neck, or breast cancer; it should not be given to patients that have a high chance of recovery, or to young patients. I met all three criteria.

## **Remission**

Through it all, I overcame the obstacles and struggles and finished treatment in July 2006. In September, I accepted a full time job working in cancer research at a University Health Center Institutional Review Board away from my tribal community but within an IHS urban service area. While filling out my insurance forms, I inquired about pre-existing conditions. The insurance provider said that if I could verify continued coverage with no lapses in service then they would cover the pre-existing condition. I explained that I was always eligible for direct service through IHS. They accepted it and I had insurance coverage.

## **Relapse**

In November 2006, I began to show symptoms that my cancer had returned. Because of the problems that I experienced at the former cancer center I decided to change oncologists. I spoke with the IHS service area office’s CHS and they agreed to be the secondary provider to what my insurance company did not cover even though my new doctor was not a doctor they contracted

with. The plan of treatment was for extensive salvage chemotherapy and an autologous stem cell transplant. My transplant would consist of 30 days in the hospital and more high-dose chemotherapy.

I began salvage chemotherapy in January 2007. The treatments were much more intense and longer. It took two different types of salvage chemotherapy treatments which was four total rounds to get my tumor to respond. By May, my tumor had decreased enough to begin transplant procedures.

### *Transplant*

I had been speaking with CHS and my insurance company to try to coordinate what services would be covered. CHS advised me that they would try to cover the costs that the insurance provider would not. The dilemma came when the insurance provider said that my hospital, where I was working and where I was planning to have the transplant procedure, was not in the insurance provider's network and that I would have to go out of state. CHS said that in order for me to have a chance of their office covering the remaining costs then I would need to stay in-state (even though it was a higher cost). The CHS worker informed me that I had a high chance of having my costs covered because I was a good candidate. She [CHS caseworker] said that it is not common to cover most transplants because of the follow-up costs that are associated with them and that often patients do not adhere to the follow-up treatment. Ultimately, after I had already scheduled the transplant and began the transplant procedures (stem cell harvesting, heart and lung tests) my referral was denied and my health could not afford the wait to reschedule at another facility out of state.

I was released from the hospital in June 2007 and had plans to return to Lawrence to restart law school. In July, my doctor called to say that the transplant did not remove all of the cancer cells, and I was still showing active uptake in my cells. I was immediately sent to a radiation oncologist.

### *Radiation*

I had plans to return to law school in the Fall of 2007 and because of my current obstacles with IHS and CHS I decided to not let "the wait" for referrals and approvals be the deciding factor. This "wait" for referrals may or may not produce services, and I felt that my health could not afford that gamble of getting an approval. I started school and radiation at the same time. As a result of my previous struggles, I chose to not go through IHS. The debt is 100% on me. However, I maintained contact with my area office regarding my decision to go back to school and my doctor is in Oklahoma.

Currently, I am in remission for a second time. I have outstanding medical debt as well as my credit rating has been greatly impacted. I receive CT and PET scans every six weeks to monitor any growth in the tumor, and full blood panel tests. CHS has covered two of my five scans since radiation. My biopsy bill has been paid, even though after the procedure, CHS claimed that they had not authorized the hospital stay. It took over a year to get it paid, but it has now been paid.

While, IHS covered my chemotherapy, I still incurred several other costs associated with cancer. My total cancer debt is around 200,000.

### **Other problems**

Getting the referrals and approvals was not the only problem that I encountered with IHS and the CHS system. When I was deferred and then denied the first time, I asked what the process was so that I may appeal it. I was told that I was not allowed to see the policy for approvals or denials. There was not one person who could tell me how the process worked, or how often the committee met, or explain the criteria for approvals.

At the cancer center where I was referred the financial manager informed me of her issues of dealing with me because I was from “the Indian Clinic”. I corrected her and told her that I was not referred from a clinic but from a Hospital and it was actually my tribe, not the hospital that was the payor. She proceeded to tell me how “the Indian clinic likes for us to treat their patients, but they don’t want to pay us.” I was frustrated by her attitude, dislike for IHS, and blatant racism; however, it was not my issue to deal with. I was a patient like every other patient, battling cancer and fighting for my life. I was very concerned that perhaps I would be treated differently and would not receive the highest standard of care because I was an “Indian patient”. Each time that I went in for treatment the front desk would ask me for my “Indian authorization” or my “Indian papers” before they could treat me. They did this very loudly, and I often felt embarrassed by the scene that they caused.

During treatment I often needed to get CT scans to monitor the size of my tumors. I would go to Claremore IHS to get the scans and often during the scans the CT machine would overheat and would have to be shut down for a while to let it cool it off. It has been suggested by other doctors that I may not have had adequate scans because the machine at Claremore IHS was older and probably did not show the true picture of my cancer. Therefore, it is likely that I may have never truly been in remission.

### **Purpose of my Testimony**

Through all of the struggles, I understood that I was fortunate to have access to what health care I did receive. Having worked on IHS contracts in prior jobs, I understood the budget process and that there is never going to be enough money to meet the entire medical need of the community. But, I truly believe that had someone been more willing to walk me through the process in the beginning I may have had a different experience. I, like so many others was very disillusioned by the true nature of the system. Never throughout my entire experience did I feel empowered or in control of my own health. If I would have had a choice on what my options were in the beginning I may not have had to suffer so much. Since then, I have been told by several doctors, oncologists, and surgeons that I should have never had my chest cracked open in the first place. I did not have a choice and since then my struggles with the system lead to longer treatment time for a tumor that was even larger than was originally noticed. I will forever bear the scar and at 30 years old I have already been through menopause as a result of my treatment. I am happy to

be alive and have the opportunity to share my story, but, I cannot help but to wonder what would be different if I had only known.

Thank you