

*Written Testimony  
Of  
Erinn Ackley  
(Daughter of William Ackley, Red Lodge, MT.)*

*Domestic Policy Subcommittee  
Oversight and Government Reform Committee*

*Wednesday, September 16, 2009  
2154 Rayburn HOB  
10:00 a.m.*

*“Between You and Your Doctor: the Private Health Insurance  
Bureaucracy.”*

Mr. Chairman and Members of the Subcommittee,

Thank you for inviting me to participate in today’s hearing on health reform. I am honored to be given the opportunity to convey my family’s struggle with the administrative measures and protocols used by my father’s private health insurer and the lengths we went through to obtain his doctor-prescribed treatment in the form of a bone marrow transplant.

In 1986, my father, William (Bill) Ackley, was diagnosed with Chronic Lymphocytic Leukemia (CLL) at the age of 39. CLL mainly affects people over 60 and is rare in people under the age of 40. Dad was an avid sportsman and maintained a healthy lifestyle. He was especially devoted to running, competing in numerous races, including marathons, even after his diagnosis. Until 2001, he and his oncologist were able to keep his disease from progressing and interfering with work or family and social obligations through intermittent cycles of oral chemo medication. In 2001, his disease reached a stage where more aggressive treatment was necessary, and he underwent IV chemotherapy treatments for approximately four months, which put the disease into remission. In 2003, at the age of 56, he retired from a 31-year career in elementary education as a teacher, principal, superintendent, and coach in the state of Montana. Upon his well-earned retirement, he and my mom, Marjory, moved to Ormond Beach, Florida. He retained his health insurance through the Troy Public School District group coverage plan through Blue Cross Blue Shield of Montana (BCBSMT), the same insurance coverage he had for all but the first year after his CLL diagnosis.

**June-September 2005:** In June of 2005, his CLL became active again, and he began IV chemo treatments as prescribed by his oncologist in Ormond Beach. By September 2005, it was evident that the chemotherapy was not effectively managing his cancer, and he was referred to Shands Hospital at the University of Florida in Gainesville. Shands has one of the top bone marrow transplant centers in the nation, and my father was accepted into their transplant program.

**October-December 2005:** The testing of my father’s three siblings did not find a transplant match. A search for a non-related donor began in October 2005 through the National Marrow Donor Program. The best of four

suitable donor matches was selected on December 1, 2005—Shands had found the anonymous person who was willing to selflessly let the stem cells from his/her marrow be harvested for my dad's transplant.

**January 4-February 14, 2006:** On January 4, 2006, transplant evaluations at Shands Hospital were scheduled to begin. My father was admitted to a local hospital in Ormond Beach on January 30, 2006, for large doses of chemotherapy ("salvage chemo") to eradicate as much of his disease as possible in preparation for transplant. After 15 days, he was discharged on February 14, 2006.

**February 28-March 28, 2006:** After reviewing CT scans and other test results, his doctors at the Bone Marrow Transplant (BMT) Unit at Shands Hospital requested that my dad have another round of inpatient chemotherapy in Ormond Beach. He was readmitted to the Ormond Beach hospital on February 28, 2006, for his next round of intensive "salvage" chemotherapy. After nearly a month, on March 25, 2006, my father was discharged and then traveled to Shands Hospital on March 28, 2006, for pre-transplant tests.

**April 13, 2006:** On April 13, 2006, my dad met with his transplant doctor at Shands, Dr. Jan Moreb, and received the great news that the tests of the past couple weeks indicated his CLL had responded well enough to the two rounds of aggressive inpatient chemo that they were ready to proceed with the transplant. My dad signed his releases for treatments and trials. At this point, BCBSMT had covered my dad's expenses for his outpatient and inpatient pre-transplant treatments and tests, as well as the testing of donors identified through the National Marrow Donor database. On April 14, 2006, Dr. Moreb made a formal request for authorization from BCBSMT for a non-myeloablative transplant, also known as a "mini transplant." "Mini transplants" had been successfully used on CLL patients and are characterized by giving patients less intensive dosages of chemotherapy than standard transplants, resulting in fewer side effects.

**April 18, 2006:** BCBSMT informed the Bone Marrow Transplant Unit at Shands on April 18, 2006, that they had asked an outside "qualifier" to look over my father's case. The BMT coordinator at Shands stated to my parents that the hospital had never had any problems with approval for the mini transplant for CLL patients through Blue Cross Blue Shield of Florida and was optimistic that BCBSMT would also approve the procedure. Shands had submitted 46 pages of abstracts, studies, medical reviews, and statistics in support of the transplant protocol when it was submitted for approval. In an e-mail at this time, as he waited for word from BCBSMT, my dad stated "These guys are just playing with my life."

**April 20, 2006:** Two days later on April 20, 2006, the BMT coordinator at Shands was notified that the "mini transplant" procedure was denied by BCBSMT and immediately informed my parents of the denial. The doctor who made the determination for BCBSMT cited an outdated 2003 article as the justification for classifying the mini transplant as "investigational" for treating CLL patients. It is important to note that, at this time, CLL was one of the diseases listed as covered for transplant under federal funding guidelines, including those used for Medicare and Medicaid. It was not until four days later, on April 24, 2006, that my parents received notification by letter from BCBSMT.

**April 26, 2006:** On April 26, 2006, the consensus among the transplant doctors in the BMT Unit at Shands Hospital was that my dad should request an expedited appeal of the mini transplant, as that was the preferred treatment and my dad's "life or health would be seriously threatened by the delay of a standard 60 day reconsideration process." Dr. Moreb from Shands provided additional abstracts to BCBSMT to demonstrate response rates in more recent data refuting the statistics from the 2003 article that was used to justify the transplant denial. My mom began phoning and faxing back and forth between Shands Hospital and BCBSMT to set the expedited appeal in motion. On this day, my family contacted the Montana Insurance Commissioner's Office in an attempt to enlist their assistance with overturning the denial of my dad's bone marrow transplant.

**April 27, 2006:** The next day, on April 27, 2006, the Montana Insurance Commissioner's Office contacted BCBSMT requesting a copy of the Troy Public School's group coverage plan. Until the Insurance

Commissioner's office received written verification from BCBSMT that Troy Schools did not have a "self-funded" plan (they did not), the commission had no jurisdiction. On this day, the expedited appeal was in the hands of the Mountain Pacific Quality Health Foundation in Helena, Montana. The Montana Department of Public Health and Human Services had designated the Foundation as the organization that would perform the independent review. The Foundation was to have notified the member (my father), the provider (Shands Hospital), and BCBSMT of its decision within 48 hours (not including Sunday). As of May 2, 2006 (five days after the Foundation had received my dad's expedited appeal), neither my father nor Shands had received notification of the Foundation's decision.

**April 28, 2006:** By April 28, 2006, the BMT Coordinator at Shands had supplied information specific to the history of mini transplants at Shands to BCBSMT and the Insurance Commissioner's Office. Shands had begun performing mini transplants six years earlier in 2000. From 2003-2006, Shands performed mini transplants on 37 patients with various diagnoses. Three of those mini transplants were performed on patients with CLL. Two of the three people with CLL had Blue Cross Blue Shield coverage from states other than Montana.

**May 1, 2006:** On May 1, 2006, my family and a network of family and friends from across the country began a letter-writing and e-mail campaign to elected officials representing Montana in both state and national offices requesting any possible investigation or intervention to hold BCBSMT accountable for the transplant denial which was endangering the successful treatment of my father's disease and his life.

**May 3, 2006:** On May 3, 2006 (six days after the Foundation had received my dad's expedited appeal), the BMT Coordinator at Shands informed my dad that the expedited appeal did not reverse the original denial of the mini transplant. My parents did not hear directly from BCBSMT until a letter was received in the mail three days later, on May 6, 2006. The BMT Coordinator told my parents that Shands would submit another protocol for a "full transplant," a procedure that had been performed at Shands for nearly 20 years. Shands is only one of the more than 70 transplant centers across the United States affiliated with the National Marrow Donor Program that performs bone marrow transplants on CLL patients. This is not an investigational or untried treatment for CLL.

**May 7, 2006:** In support of my dad, employees of Troy Public Schools contacted their insurance representative on May 7, 2006, in the hope that the insurance representative could personally contact BCBSMT and assist my father in receiving his prescribed treatment.

**May 12, 2006:** On May 12, 2006, Shands' BMT Coordinator informed my parents that the full transplant protocol was also denied on the terms that the transplant was an "investigational" treatment for CLL patients. At this point, the Montana Insurance Commissioner's Office still had not even been able to obtain a copy of my dad's insurance plan that was originally requested (and repeatedly requested thereafter) 16 days previously. The Bureau Chief of Policyholder Services from the Montana Insurance Commissioner's Office even volunteered to walk over to the BCBSMT office three blocks away to pick up the documents by hand.

**May 15, 2006:** Another letter-writing campaign to Montana's elected officials ensued on May 15, 2006. The staffs of some of these officials made inquiries to the Montana Insurance Commissioner's Office and BCBSMT trying to find a way to intercede within legal guidelines. If not before, BCBSMT was now aware of the interest its denial of my dad's transplant was generating.

**May 23, 2006:** As a last resort, my parents contacted the Blood & Marrow Transplant InfoNet Patient Advocacy group requesting a referral to an attorney who had experience with similar cases. In the following days, my family was referred to an attorney in Virginia with experience in litigating transplant denial cases. Pertinent documents were delivered to him on May 23, 2006, and subsequent consultation occurred soon thereafter. The attorney reviewed the denial letters, insurance policy, and letters from my dad, his doctor, and the National Marrow Donor Program Office of Patient Advocacy. The attorney said he was at a "loss" as far

as BCBSMT's denial on the grounds that the transplant procedure(s) are "investigational," since a transplant is standard protocol for a patient with CLL in the stage that my dad was experiencing.

**May 26, 2006:** After speaking with the attorney, it was decided that my dad would request an expedited appeal of the denial of the second proposed (full) bone marrow transplant protocol. Request for this expedited appeal was faxed to BCBSMT on May 26, 2006, accompanied by a letter from Dr. Moreb and a letter from the National Marrow Donor Program. The National Marrow Donor Program also provided nearly 40 pages of compelling documentation, including clinical studies and journal abstracts, to "Illustrate that allogeneic (non-related donor) transplant for the diagnosis of CLL is neither investigational nor experimental."

At this time, the Insurance Commissioner's Office finally had secured a copy of the BCBSMT contracts for the Troy School District health insurance plan and was proceeding with a review. The Insurance Commissioner's office called BCBSMT to inquire whether they had received my father's request for a second expedited review. The call ended up in voicemail, and they received no response. The Insurance Commissioner's office also contacted the BMT coordinator at Shands inquiring whether the medical director at BCBSMT had made an attempt to speak with Dr. Moreb. The BMT coordinator replied that no attempt had been made. Under Montana code 33-32-201(4), a "determination made on appeal or reconsideration, that health care services rendered or to be rendered are medically inappropriate may not be made unless the health care professional performing the utilization review has made a reasonable attempt to consult with the health care provider." It seemed that BCBSMT was in non-compliance with this statute, and subsequent to the Insurance Commissioner's Office addressing this, the BCBSMT doctor did finally call and speak with Dr. Moreb the following week.

A nephew of my dad who lives in California and is an insurance company executive discovered that a doctor who was one of his colleagues knew a doctor in Montana with a personal connection to the President of BCBSMT. The Montana doctor volunteered to try to facilitate a direct conversation between BCBSMT's President and myself. This turned out not to be possible, but he did converse with me before talking with her himself, making her personally aware of my dad's treatment denials and appeals.

**May 30, 2006:** On the same day that this doctor spoke directly to the BCBSMT President, May 30, 2006, the Montana Insurance Commissioner's Office delivered a letter and several documents to BCBSMT asking for a response by noon the next day (May 31, 2006) regarding my dad's situation. Also on this day, the Troy Public School's insurance representative had a conference call with the Medical Director and the President of BCBSMT. All of these connections were aware of the fact that my parents had been in consultation with an attorney.

**May 31, 2006:** BCBSMT replied to the Montana Insurance Commissioner's Office on May 31, 2006, that my dad's expedited appeal had been delivered to the "Foundation" for *two* peer reviews on the morning of May 30 and that there was no way BCBSMT would have a response back from the Foundation by noon on May 31, as had been requested by the Insurance Commissioner's Office.

On May 31, due to the delay in obtaining authorization for the transplant first submitted by Shands a month and a half previously (on April 14, 2006), my dad's cancer was once again growing rapidly, and my dad had to be readmitted to the Ormond Beach hospital for another round of intensive "salvage" chemotherapy.

*In an e-mail dated June 1, 2006, my mom wrote, "Dad is so counting on a reversal of the denial this time around and I think that is why his frame of mind (and even his physical energy level, appetite and mental focus) is so improved the past few days."*

**June 2, 2006:** After weeks of trying for a face-to-face meeting, on June 2, 2006, the Bureau Chief of Policyholder Services from the Insurance Commissioner's Office was finally able to meet with someone from BCBSMT and express her concerns about the appeal process of my dad's transplant denial.

**June 7-9, 2006:** The insurance representative for Troy Public Schools informed my parents five days later, on June 7, 2006, that BCBSMT had reversed the denial and decided to cover my dad's transplant. Two days later, on June 9, 2006, my parents received a faxed copy from the Insurance Commissioner's Office of the letter from BCBSMT stating approval for my dad's transplant. The staffer at the Montana Insurance Commissioner's Office had been waiting all day to receive the official letter from BCBSMT. She stayed past her normal work hours to receive the document at 5:00 pm (MDT) and fax it to my parents in Florida. The peer review that BCBSMT decided to go with was a second one that leaned toward the non-myeloablative transplant (the mini transplant protocol originally submitted in April) over a myeloablative ("full") transplant.

**June 10, 2006:** The next day, June 10, 2006, my parents received a letter in the mail from the Foundation based on the opinion of the *first* peer review doctor (the doctor who denied my dad's first appeal) stating that he had not changed his mind and still believed that the transplant was "investigational" regardless of the different protocol submitted. If not for the staff at the Montana Insurance Commissioner's Office who had faxed the letter overturning the denial the night before, my parents would have believed the Foundation letter upholding the denial of full transplant was the final decision of BCBSMT, resulting in more emotional pain.

**June 12-13, 2006:** Two days later, on June 12, 2006 (13 days, not 48 hours, after the Foundation received the appeal), my parents finally received a letter from BCBSMT stating what the Troy Public School's insurance representative had told them five days earlier: The denial of the medical necessity of my dad's transplant had been overturned. The next day, on June 13, 2006, my parents received another letter from BCBSMT that had "CORRECTED LETTER" in bold type on the top and had inserted (also in bold type) into the original letter that my dad could have either the non-myeloablative (mini transplant) or myeloablative (full) transplant. In the end, both denials were reversed, *two months after* my dad's doctor requested approval for prescribed treatment.

At this point, it is important to once again remember that the bone marrow transplant that had been denied to my father as experimental and investigational by BCBSMT was a covered treatment under federal funding guidelines, including those used by Medicare and Medicaid for CLL patients. Had my dad been a few years older with Medicare coverage, his transplant would have been approved in April of 2006.

Because we had no central advocate to turn to during the agonizing process leading up to BCBSMT overturning its denial of my dad's transplant, we had to enlist the help of numerous others to fight on behalf of my father and persuade the insurance company to approve his prescribed treatment. Just how many people did it take?

- It took dozens of friends and family who wrote letters and sent e-mails to anyone in a position of authority they thought could help.
- It took the doctors and staff of the Bone Marrow Transplant Center at Shands in Gainesville, who spent countless hours documenting the necessity of my dad's transplant with a compilation of research documents and abstracts and devising a transplant treatment protocol that would be accepted.
- It took the support staff at the National Marrow Donor Program, who took the time to assemble more than 40 more pages of scientific data in support of the transplant.
- It took the dedicated staff in the office of the Montana Insurance Commissioner's Office, who persisted in keeping BCBSMT in compliance with the regulations of the appeals process and spending extra time to keep our family updated on events when the insurance company itself did not.
- It took the local representative of Troy School's BCBSMT health plan, who tried to personalize this case to the executives of BCBSMT.
- It took the connected individuals stretching from my cousin in California to the President of BCBSMT and the time they gave to help a person they had never met but whose cause they supported.
- It took the attorney in Virginia, whose reputation certainly signaled to BCBSMT the seriousness of my parents in pursuing all avenues to overturn the denials.

- And most of all, it took the unwavering persistence of my parents, who refused to accept that the unreasonable denial of my dad's transplant by an insurance company would be the deciding factor in my dad's life-and-death struggle with the disease he had lived with for 20 years.

At no time during this life-consuming denial and appeal process were my parents able to speak with a "real person" at BCBSMT. The only people my parents could get hold of on the phone were service representatives, who could only refer my parents to the steps listed for appeal on the denial letters. The service representatives were unable to connect my parents with a person who could discuss my dad's case or even give my parents a phone number to reach such a person. All correspondence with BCBSMT occurred in front of a faceless fax machine, and all of BCBSMT's communications with my parents was via USPS mail that lagged by critical days the decision dates on the denials of prescribed treatments and the decisions on my dad's expedited appeals.

One would think the paying member would be valued enough that he/she shouldn't have to rely on third parties such as hospital staffs, group plan representatives, or staff members of the state insurance commissioner's office to notify him/her of appeal process outcomes as they happen. Why should third parties be notified via phone or fax while the member waits for the USPS to carry letters across the country?

**August 17, 2006:** Due to the selfless diligence of an anonymous donor who had been scheduled and rescheduled, was subject to multiple physical exams, received daily drug injections for five days prior to the donation to help move blood-forming cells out of his/her marrow into his/her bloodstream and for 4-6 hours donated his/her stem cells at an apheresis center, my dad did have his bone marrow transplant on August 17, 2006. It took from June until mid-August for him to finish the last inpatient chemo regimen begun on May 31 at his local hospital, be re-evaluated once again for transplant at Shands, go through several weeks of blood growth factor injections to increase his blood counts to a level where it was safe to start pre-transplant treatments and enter into the transplant protocol of chemo and radiation at Shands in Gainesville in the Bone Marrow Transplant Unit. The protocol that was finally used was midway between the mini- and full transplants.

**January 3, 2007:** Though the results of the transplant initially looked promising, within a couple of months, the cancer cells in my dad's bone marrow began winning the fight against the healthy donor cells. My dad was never able to return home to Ormond Beach from Shands in Gainesville. He celebrated Christmas in his hospital room in the Bone Marrow Transplant Unit with my mom Marjory, my husband Dan, and me—a room that we decorated with a small tree, garlands, and lights. My dad, from his hospital bed hooked up to IVs, told us in all sincerity that it "was the best Christmas I ever had." He made it into the New Year, but on January 3, 2007, at the age of 59, he passed away.

Would there have been a different end to my dad's story if he had been given approval of the first transplant request in April 2006? Would he be alive today to play with his only grandchild, Eliza, who was born 17 months after his death? We don't know. What we do know is that his chance for survival most assuredly did not increase because, after supporting and paying for the prescribed treatments deemed necessary for the control and suppression of his disease for 19 years, Blue Cross Blue Shield of Montana built the bureaucratic roadblocks that changed the course of my father's treatment and made him wait four months for his potentially life-saving bone marrow transplant.

Respectfully submitted by,

Erinn C. Ackley  
Red Lodge, Montana