

***Statement  
Of  
Mr. Mark Gendernalik  
West Hills, California***

***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, Members of the Subcommittee:

Thank you for the invitation to testify today.

I am a schoolteacher with the Los Angeles Unified School District. A profession I chose in large part because it offered the benefits, especially health coverage, to allow me to provide for my family. About two and half years ago my wife, Bertha, and I welcomed twins into the world, a boy and a girl. Carter and Sidney arrived early, but thrived from the get go. They were soon home. All was well and they grew daily. Just before her three month "birthday", Sidney began experiencing weird episodes where her arm would jut out into full extension as she was falling asleep. The pediatrician advised us to watch the "seizures" closely, and I began to video tape their progression.

Soon we were referred to a pediatric neurologist, Dr. Roger Huf and the complicated cycle of referrals began. Dr. Huf started Sidney on an anti-seizure medication called Trileptal and ordered an MRI with contrast dye done at UCLA, with which he was affiliated. Regal Medical Group the agent for my HMO, Pacificare, denied the referral. In the meantime, Sidney returned to the Dr. Huf's office for an EEG. Regal Medical Group sent Sidney to the San Fernando Valley Interventional Radiology and Imaging Center, who could not administer the contrast dye into my infant daughter, because her veins were too small. I assume Regal saved some money, but Dr. Huf did not get the complete MRI he sought. Dr. Huf diagnosed Sidney with epilepsy.

Sidney continued to decline and become spacey and withdrawn. The seizures worsened. As a result Dr. Huf's diagnosis changed to a condition called Infantile Spasms. By November 8, 2008 we agreed with Dr. Huf to seek a second opinion, to confirm or refute this new diagnosis. Pacificare/Regal authorized us to take Sidney to Children's Hospital Los Angeles (CHLA) for a second opinion, but refused to allow CHLA to perform a new

EEG. Their stated reason was that CHLA was non-contracted. I have come to understand from the MRI experience non-contracted means too expensive. We called Children's Hospital Los Angeles immediately and thanks to my wife Bertha's persuasive speaking skills we managed to get an appointment for December 10, 2008. The new neurologist, Dr. Wendy Mitchell required us to bring an EEG. Dr. Huff had been authorized to conduct the new EEG but would be unable to accommodate us. Thanks again to Bertha's tenacity we were able to get sent to another neurologist, Dr. Raafart Saad Iskander, for the expressed purpose of having another EEG taken. Dr. Iskander told Bertha the EEG supported the diagnosis of infantile spasms.

At last, the misdiagnoses, the eleventh hour EEG, and time-consuming referral process were behind us. My wife took the day off work and made the trek into Children's Hospital Los Angeles. We were filled with hope that we might get an accurate diagnosis and help our daughter come back to us. The new (now third) neurologist, Dr. Mitchell, examined our daughter and the EEG report. She expressed dismay that it took approximately six months to get an accurate diagnosis and begin treatment for Sidney's degenerative condition. She immediately ordered Sidney to be admitted and commence a twenty-four hour EEG with video telemetry, as well a new MRI of Sidney's developing brain.

By this time I had begun doing my own research, and expected this, as it is the standard protocol recommended by the American Society of Pediatric Neurologists. Hopes were dashed again, when my wife called with the news that Pacificare/Regal had denied the request for the hospital monitoring and test. I immediately got on the phone with Regal and questioned them as to how THEY authorized the neurologist for us to see for an informed second opinion, and then refused to authorize the standard diagnostics necessary to create the informed second opinion we sought. They had no answer.

Soon however they claimed to have issued the referral for UCLA and provided an address for us to take Sidney to. They said the UCLA staff would be awaiting Sidney's arrival. I pressed them for an explanation. Their representative said their medical manager preferred UCLA. I countered that (A) They didn't like UCLA when the first neurologist requested the first MRI be done there and (B) Why then did they send us to Children's Hospital in the first place? I suggested this had more to do with dollars and cents, than what made good medical sense for my daughter. They told me I'd have to file a formal complaint to get my answers.

I called my wife, who was still waiting in Dr. Mitchell's office at Children's hospital. I relayed the address that the Regal Medical Group staffer had provided to me. She relocated to UCLA medical center, but found the address led to an administration building. Obviously at a wrong address, she again phoned me for assistance. I located an address for the UCLA Mattel Children's Hospital and guided her there over the phone. Upon arrival at the hospital, they put her and Sidney in the emergency ward. Bertha waited several hours as UCLA, struggling to make sense of the situation. They had not received a referral. Eventually, the final school bell rang and I drove to UCLA medical center to see my Sidney. Shortly after my arrival, Dr. Daniel Arndt came into the room

and told us we had to go home as they had no beds available for Sidney. We were told to expect a call in the next couple of days.

After a couple of long days of waiting, the call came to say that they had a bed for us. I took Sydney back to UCLA. The medical staff began to administer the twenty-four EEG. The following day the team of doctors reported that they concurred with the diagnosis of infantile spasms. Next they mentioned a drug I had read about, ACTH. They also mentioned it was an expensive drug and a course of treatment could cost over \$100,000. No problem I've got insurance... right? Well, no.

Over the next seven days, Pacificare/Regal refused to authorize the drug. Our doctors had their telephone calls go unreturned, while Bertha and I fared no better. Pacificare/Regal was determined not to pay out this claim. Finally, after a week of watching my daughter continue to degrade in a hospital crib, and the doctors of the pediatric neurology team become demoralized, Dr. Arndt said they would have to discharge Sidney without the ACTH treatment. I implored him to give us one more day to get this resolved. Bertha and I worked the phones. I was hung up on by both Regal medical Group and Pacificare, for making the unreasonable request to speak to a supervisor. I eventually called the state capital in Sacramento, and found the Department of Managed Health Care. I was connected to a Nurse, I believe it was Anita Watson, who was able to listen to my concerns and take down the information and begin looking into the problem. She phoned me not long after and said her research confirmed the doctors' recommendation. She also said she would place a phone call to Pacificare. About an hour later both Bertha and the doctors at UCLA received the long-awaited phone call from Regal Medical Group with the authorization number for the needed drug, ACTH. We began the treatments soon after.

The toll it took upon my family will never be forgotten. The constant hassle of getting referrals for the correct services. The run-around to get the needed tests. The over-a-week recovery time lost to my daughter while we languished waiting for her meds. The months lost to an inaccurate diagnosis. The battle to get the medication approved. We did everything right. We worked hard and earned good medical coverage to protect us. Unfortunately, Sidney developed this rare and unexplained condition. Unfortunately she required extensive medical treatment. The one thing we can agree upon with the HMO is that we both wish Sidney had never gotten sick. We would have a completely healthy daughter and they could keep their money.

Consumers should not have to endure this kind of life-and-health threatening hassle. I hope Congress will find better ways to ensure that insurers deliver on the care they promise.

## Continuing hassles

Unfortunately, the ACTH treatment was not successful. Sidney kept seizing, and kept losing ground on her developmental milestones. The treatment team at UCLA now recommended Vigabatrin. We expected this because that is what the research we had been reading suggested was the next line of defense. Vigabatrin came with its own perils. In particular it was known to be retina toxic and had the potential to damage the retina leaving the user with a reduced vision field.

Bertha and I were faced with a terrible decision. Do we risk our daughter's vision in order to grant her the best possible chance at a future complete with normal cognitive functioning, or do we maintain her sight and doom her to an almost certain future of severe mental retardation. We chose to proceed with the Vigabatrin treatment.

The doctors at UCLA had us complete a several page waiver explaining the risks of Vigabatrin and just as importantly the standard protocol designed to mitigate those risks. The protocol consisted of a series of specialized retina exams. First, there was an all-important initial, or baseline, exam to document the form and condition of her retinas before the drug had time to affect them. Then, there would be others to follow. Each subsequent exam would be compared to the first to evaluate the extent that any damage was occurring. This information would be weighed against any benefit the drug was offering, and we would make a decision to continue or not.

We began the treatment in late April of 2008. The referral for the retina exams was submitted to Regal Medical Group at that time. We were sent to Children's Hospital Los Angeles, where we received a June 23, 2008 authorization to see a Dr. Thomas Lee. Before the appointment to see Dr. Lee could be made, Bertha was informed by Children's Hospital that the appointment would be delayed because Regal Medical Group and Dr. Lee had not agreed upon a "rate sheet", or contract. Bertha called Regal Medical Group only to be assured that this would be resolved. It wasn't. After weeks of waiting the authorization was cancelled.

Next, Regal Medical group promised to make good on this situation and issued an authorization to Children's Retina Institute and a Dr. Khaled Tawansy. The Regal staff assured us that they had a contract with Dr. Tawansy and that he was approved to conduct the exam. Dr. Tawansy and his staff were the utmost in professionalism, received us for the initial consult and scheduled the retina exam for Huntington Hospital in Pasadena, California. On August 1, 2008 Regal Medical Group issued an authorization for the procedure to be conducted at Huntington Hospital. It was now three months after we were supposed to have the "baseline" exam conducted, but at least we were finally getting it done. More importantly we might get some idea if our baby girl's vision was still intact.

All was not as it seemed. Dr. Tawansy phoned on Saturday, August 2, 2008. Sidney was scheduled to go into surgery at Huntington Hospital the following Monday early in the

AM. The hospital had already called to take care of preadmission instructions. Dr. Tawansy seemed uneasy as he began to explain. He had received a phone call from Dr. Jeffrey Klein, Senior Medical Director at Regal Medical Group after 8:00 the night before. He asked if Dr. Klein had called us. We had not received any phone call from anyone at Regal Medical Group. He started by saying that Dr. Klein wanted him to move the surgery to a surgical center in Lynwood, California. I said, "No way." It soon became clear that Dr. Klein had cancelled the authorization, and if we went ahead as scheduled my family would have to cover the costs. Not a possible option. Dr. Tawansy in no way left me with the opinion that it was his first choice option. He remarked that he had already arranged for the equipment at Huntington Hospital. He also said that Dr. Klein suggested he tell us moving the procedure would save about seven thousand dollars towards Sidney's future care. I told him I have an unlimited policy and only Regal Medical Group would be saving money. Not only was Sidney going to face another delay, she was having her care downgraded to save the Medical Group some money.

I phoned the number Dr. Tawansy provided for Dr. Klein and left a message on his voicemail. I called all three numbers available on my Pacificare membership card. All three departments were closed, with no way to reach a live operator. I did receive a phone call from Joann at Regal Medical Group who informed me the authorization was no longer valid, but she would attempt to reach Dr. Klein.

Medical Group did authorize the procedure to be conducted by Dr. Tawansy at M/S Surgery Center in Lynwood, California. Worried about the traffic, I arrived especially early on the morning of November 21, 2008. As I drove up to the building, I was greeted by gang graffiti upon one of its walls. Not the kind of welcome I had hoped for. When the facility opened for business, I was greeted warmly by the staff and lead to a waiting area. The gentleman nearby was there for a worker's compensation injury. Others I saw as the day progressed appeared to be getting corrective laser eye surgery. As I waited for my daughter to be called in for Sidney's prep, I noticed a man who appeared to me to be a medical vendor of some sort. Unfortunately, Sidney and I spend a lot of time in doctor's offices and have seen far too many pharmaceutical sales representatives. This gentleman looked the type and asked for Dr. Tawansy at the receptionist counter. After he was lead back I confirmed with the receptionist that he was there to see Dr. Tawansy. Later, Dr. Tawansy would tell me that the surgical center didn't have the necessary equipment either he or his organization had to buy it. The vendor had been there to deliver it, as well as review its operation, just minutes before it was to be used on my daughter.

In the end, almost seven months after we were supposed to establish a baseline, Sidney did get the eye exam she needed. To the best of Dr. Tawansy's abilities she has maintained healthy retinas. Due to her cognitive deficits she is unable to report any problems with her vision. Ultimately the Vigabatrin did not produce good enough seizure control to warrant its risks. We discontinued treatment with it by March of 2009.

Consumers should not have to endure this kind of life-and-health threatening hassle. I hope Congress will find better ways to ensure that insurers deliver on the care they promise. The stress of constantly having to hold the HMO and their agents to their agreed

upon obligations has relegated me to the role of my daughter's care manager, and all to often robbed me of my role as Sidney's loving daddy.

Sidney Gendernalik  
Relevant Chronology

**Delay of Service: Withholding Authorization for ACTH**

- 03-20-2007 Born as twin B at 32 weeks gestation spent 7 days in the Neonatal Intensive Care Unit (NICU) in order to make benchmarks for discharge. Unremarkable stay, breathing unassisted and feeding well.
- 06-29-2007 Approximate date parents first noticed unusual stiffening of right arm and head. Father, Mark Gendernalik, was holding her as it occurred.
- 07-02-2007 Sidney is taken to her pediatrician, Scott Calig, regarding unusual movements for the first time. Dr. Calig suggests it may be *hypnogogic Phenomena* as each occurrence is closely related to sleep. Advises the parents to watch carefully for any changes.
- 07-12-2007 Sidney's father returns to the pediatrician with a videotape of recent episodes Sidney has experienced. Dr. Calig suggests a referral to a neurologist.
- 07-25-2007 Sidney's first exam by neurologist, Roger Huf. Dr. Huf prescribes Trileptal (Oxcarbazepine). Dr. Huf requests MRI with contrast to be conducted at UCLA Medical Center and an EEG.
- 07-27-2007 Sidney undergoes an EEG at Dr. Huff's office; Begins treatment with Trileptal (ovcarbazepine).
- 07-28-2007 Regal Medical Group (agent for PaifiCare insurance company) denies authorization for UCLA Medical Center, and instead authorizes San Fernando Valley Interventional Radiology and Imaging Center to conduct the MRI. Dr. Huf's office is authorized to conduct the EEG.
- 08-09-2007 San Fernando Valley Interventional Radiology and Imaging Center conducts the MRI, but fails to successfully inject the contrast dye. The resulting MRI is adequate but not as thorough as hoped for. It does not however reveal any structural damage or defect to Sidney's brain.
- 10-26-2007 On or about this date Sidney is taken off the Trileptal due to a lack of progress and parental concerns.
- 11-08-2007 Due to inferential nature of the diagnosis of infantile spasms, Sidney's parents and Dr. Huf agree to seek a second opinion to potentially confirm diagnosis of Infantile Spasms. Dr. Huf recommends a new EEG and treatment with ACTH or Vigabatrin. On or about this date Dr. Calig

initiates referral to Children's Hospital Los Angeles for second opinion and new/updated EEG.

- 11-13-2007 Regal Medical Group denies a new EEG at Children's Hospital Los Angeles, but does authorize Dr. Huf to conduct a second EEG. Dr. Huf refused to do so citing scheduling concerns.
- 12-04-2007 Regal Medical Group cancels EEG authorization for Dr. Huf and issues a new authorization for a new neurologist, Dr. Raafart Saad Iskander.
- 12-07-2007 On or about this date, Dr. Raafart Saad Iskander conducts EEG.
- 12-10-2007 Sidney is seen by Dr. Wendy Mitchell, Children's Hospital Los Angeles. After Dr. Mitchell reviews case notes and examines Sidney she makes the following recommendations: a video EEG, organic workup, metabolic workup, lumbar puncture, and new medication, possibly ACTH. Regal Medical Group, via telephone, refuses to authorize Dr. Mitchell to conduct any of the above tests. Sidney's father telephones Regal Medical Group, while Sidney's mother, Bertha Valentine, awaits resolution in Dr. Mitchell's waiting room. Regal employee responds by issuing a new referral authorization for UCLA Medical Group. The Regal representative provides an address and assures Mr. Gendernalik the authorization will be faxed over. Ms. Valentine is relayed the address and departs for UCLA, only to find the address was incorrect and blocks away from the correct location. After getting the correct address from Mr. Gendernalik, she and Sidney arrive at UCLA Mattel Children's Hospital to find that no one there has any idea who they are or why they are there. The referral never arrives. Eventually Mr. Gendernalik is off work and joins Sidney and Bertha in the emergency room. UCLA fellow, Dr. Daniel Arndt reviews Sidney's case with the family, explains there are no beds available, and discharges the family with a plan to contact them once a bed is available.
- 12-12-2007 Sidney is admitted into the UCLA Mattel Children's Hospital. An EEG with video telemetry begin.
- 12-13-2007 The EEG with video telemetry concludes.
- 12-14-2007 UCLA treatment team confirms the diagnosis as Infantile Spasms. Dr. Daniel Arndt informs Mr. Gendernalik that the team recommends ACTH, but offers concern, as there has been a recent jump in the price of the drug. He states that the hospital is contacting the insurance company.
- 12-15-2007 Dr. Daniel Arndt states the hospital has not yet received any authorization from our medical group.



- 12-16-2007 No authorization or denial.
- 12-17-2007 No authorization or denial.
- 12-18-2007 No authorization or denial.
- 12-19-2007 No authorization or denial.
- 12-20-2007 No authorization or denial.
- 12-21-2007 Dr. Daniel Arndt informs Mr. Gendernalik that the medical group has not authorized the ACTH treatment, nor even returning calls or commitments to call with a decision. The hospital will be forced to discharge Sidney. Mr. Gendernalik pleads for one more day so that he and Ms. Valentine can make an attempt to resolve the matter. Ms. Valentine contacts Regal Medical Group repeatedly. Mr. Gendernalik does likewise and is hung up on when he asks for a supervisor. Mr. Gendernalik calls Pacificare. After more than a half hour on the phone, most of that time on hold, Mr. Gendernalik is hung up on after again trying to reach a supervisor. Mr. Gendernalik then calls the California Department of Managed Health Care. He is treated respectfully by the initial staff member then transferred to a registered nurse on duty, believed to be Anita Watson. Mr. Gendernalik explains Sidney's diagnosis, the recommended course of treatment, and the problem that Regal Medical Group/Pacificare have not responded for the past seven days. He further explains the impending eviction from the hospital without adequate treatment. After approximately one hour or more, Mr. Gendernalik received a follow-up call from the California Department of Managed Health Care nurse stating that she had researched the diagnosis and treatment options. She believes that ACTH is appropriate. Further she states that she has put a call into the Regal Medical Group on Sidney's behalf. In the coming hours, Ms. Valentine receives a phone call from a staff member at Regal Medical Group with an authorization code. The Pediatric Neurology team at UCLA receive a similar phone call. By 10:12 PM Dr. Arndt is finally able to order the ACTH Sidney requires. Sidney begins her ACTH treatments.
- 12-22-2007 Over the last two days nurses train Mr. Gendernalik and Ms. Valentine how to administer intramuscular injections of ACTH. Sidney is discharged.

Sidney Gendernalik  
Relevant Chronology

**Delay of Service: Withholding, Canceling, Discounting Surgical Eye Exam**

- 04-21-2008 After several other drugs have been tried without success, Sidney's parents, Bertha Valentine and Mark Gendernalik, agree to her treatment with the drug Vigabatrin. The doctors of the UCLA pediatric neurology department counseled them about the drug. In particular that the drug is known to be retina toxic and may cause a reduction in Sidney's vision field. They are assured that this risk can be mitigated by the careful examination of her retina by a special test at the onset of treatment and then periodically throughout her treatment. An authorization for the test is requested from Regal Medical Group, and the Vigabatrin treatment begins.
- 06-23-2008 After weeks of trying to arrange for the retina exam, Regal Medical Group issues an authorization for Dr. Thomas Lee of Children's Hospital Los Angeles (CHLA) to conduct the surgical retina exam (electroretinography) Sidney requires. [This authorization was never honored as]
- 07-07-2008 Mr. Gendernalik attempts to contact both Pacificare and Regal Medical Group to complain about the delay of service. It is now more than two months since the baseline exam was to take place.
- 07-08-2008 Mary Miranda of CHLA confirms that Regal Medical Group could not agree upon a rate sheet (fees) with Dr. Lee. Mr. Gendernalik speaks with Ralph Brooks of Pacificare Dispute Resolution Department.
- 07-09-2008 Mr. Brooks of Pacificare Dispute Resolution Department states he is trying to speak with Mary Miranda of CHLA to resolve the matter. Robert Perez of Regal Medical Group calls to inform Mr. Gendernalik of a new authorization to see Dr. Khaled Tawansy. Mr. Perez confirms that Regal Medical Group does have a contract with Dr. Tawansy and the hospital needed to conduct the exam.
- 07-10-2008 Sidney is seen by Dr. Tawansy and an appointment is made to conduct the retina exam at Huntington Hospital in Pasadena, California on August 4, 2008, more than three months after the baseline exam was to supposed to occur.
- 08-01-2008 4:31 pm (as per fax date stamp) Regal Medical Group issues an authorization for the procedure to be conducted at Huntington Hospital. Huntington Hospital phones Mr. Gendernalik to conduct preadmission interview and provide preop instructions.

- 08-02-2008 Dr. Tawansy phones Mr. Gendernalik at home and states that Dr. Jeffrey Klein, Senior Medical Director at Regal Medical Group phoned him after 8:00 pm last night to cancel the authorization. Dr. Tawansy states that Dr. Klein is moving the authorization for the procedure to a surgical center in Lynwood, California. Mr. Gendernalik attempts to contact Dr. Klein without success and is told if he keeps the appointment for August 4<sup>th</sup> it will not be covered by insurance.
- 11-21-2008 Two days short of seven months after the baseline image was supposed to be taken, Sidney undergoes her retina exam at M/S Surgery Center in Lynwood, California. The facility is staffed by friendly professionals, but there are some nagging concerns. The facility was prominently marked up by gang graffiti on at least one side as Mr. Gendernalik drove up to it. The clientele consisted of a workers compensation claim, and others that seemed to be receiving corrective laser eye surgery. Dr. Tawansy had never done the procedure in a surgical center before, had to purchase the equipment just for Sidney's procedure and the equipment was delivered by the sales representative immediately before the procedure. At the conclusion of the surgical retina exam, Dr. Tawansy informed Mr. Gendernalik that the exam showed no signs of damage to Sidney's retina. While Mr. Gendernalik believes in Dr. Tawansy's professional abilities his concerns are not entirely laid to rest, as there never will be a baseline to compare with. This exam, in this location, under these circumstances was a case of too little, much too late.