

October 14, 2016

Good morning:

My name is Jeannie Sundo. I am speaking on behalf of our son Kyle Sundo who passed away nearly 6 months ago of a drug overdose. I would like to thank The Honorable Gary Tennis, the Department of Drug and Alcohol Prevention, and the HR590 task force for inviting me to share my perspective on our experience with the current "system" as it related to Kyle's substance abuse disorder and his treatment or lack thereof.

A bit of information on my husband and myself. My husband and I have been married for 31 years. He is occupational therapist and I am a sourcing manager for a multinational chemical and pharmaceutical company. We are hardworking, goal oriented individuals who have very loving relationships with our families on both sides. We have excellent private healthcare insurance.

Kyle died on Sunday, April 24, 2016. His death certificate states his cause of death as 'acute combined drug toxicity' with the manner of death as 'accidental'. Kyle was our only child who was always a sweet, kind, sensitive, fun-loving kid with good grades through his sophomore year of high school. He was always inquisitive about many things and he especially loved animals. He became a black belt in taekwondo at the age of 13.

Kyle admitted to us that he started to experiment with drugs at the age of 15. That was the same year my father died whom Kyle was extremely close with. Kyle confessed that he was so grief stricken with losing his pap that drugs were the only source to take away his pain. Kyle would often tell us he was 'broken' and couldn't be fixed. This disease of addiction caused Kyle to lose his self-esteem and any confidence he previously had in himself.

In May of 2010 Kyle's behavior changed from a sweet, kind, sensitive and fun-loving kid with good grades, to being defiant, secluded and out-of-control. His behavior and substance abuse lead to criminal behavior and he entered the juvenile court system. From March 2010 to Dec 2013, Kyle was treated for substance abuse and criminal behavior by various means (see below).

- Freeport Area School District school guidance counselors
- Children's Community Care Pediatricians in Natrona Heights, PA
- Licensed social worker in Natrona Heights, PA (behavior/family counseling)
- Family Services of Western PA in New Kensington, PA
 - Psychiatrist (diagnosed with ADHD)
 - Drug Counseling (outpatient)
- Butler Juvenile Court System – ARD program
 - Keystone Adolescent Center in Greenville, PA
 - Adelphio Juvenile facility in Connellsville, PA
 - Abraxas 1 in Marionville, PA
- Butler Hospital Emergency Room – Butler PA
- Armstrong Hospital Adolescent Psych Ward – Kittanning, PA
- Armstrong-Indiana Drug and Alcohol Prevention
- Valley Family Medicine in Cheswick, PA
 - Dr Jeffery Lineman – PCP
 - Dr Paul Brayer – Substance Abuse Specialty
- Narcotics Anonymous mtgs
- UPMC Western Psych in Pittsburgh, PA

I purposely do not plan to comment on our experiences with all treatment methods above simply because Kyle was in the juvenile court system. At that time, we weren't able to select his treatment methods and weren't necessarily focused on 'addiction' and long-term treatment. Our main focus was to cooperate with the juvenile court system to prevent Kyle with having a criminal reputation.

January 2013, Kyle admitted he was an addict and he began his journey to recovery thru various agencies. This ranged from many different medical doctors, rehab facilities, emergency rooms, outpatient facilities and recovery housing be it ½-way housing or ¾ housing. Because of his dual diagnosis, we always chose treatment methods that not only treated drug abuse but addressed his mental health issues as well.

I will now get into our experiences with the various treatment channels we pursued.

Experiences we encountered with Rehab facilities:

- Gateway Rehabilitation Center, Aliquippa, PA – Jan 2014 & July 2015
- Pyramid Healthcare, Altoona, PA – August 2014
- Cove Forge Rehab Ctr., Altoona, PA – March 2015
- Spirit Life, Indiana, PA – November 2015
- Detox/Rehab Facility, Grove City, PA – December 2015

My private health insurance paid for Kyle's stay at these facilities which included a copay of \$150. The maximum inpatient period my private insurance allowed was 28 days. Of the 28 day stay, approximately one-third of the time was for detox treatment and the remaining 2/3 was for drug counseling, This means Kyle had roughly 18 days of inpatient drug counselling. 18 days is not sufficient for inpatient treatment. If science tells a doctor that a patient needs an antibiotic for seven days, that patient is given the antibiotic for seven days. However, when science tells us that an addict in recovery needs at least a year for inpatient treatment, why does the insurance company only approve one twelfth of what treatment is required. When Kyle was discharged from inpatient rehab facilities, he was expected to manage his own follow up care via outpatient treatment centers with no oversight or assistance at all. There should be some kind of continuous follow-up care via a case worker that follows the patient (and gets to know and understand the patient).

Although we selected these facilities for their dual diagnosis capabilities, we do not feel that his mental health issues were adequately addressed. He did not receive 'complete' care treatment.

I am not familiar with the qualifications of a rehab therapist or counselors. In my experience, many of these therapists/counselors do not appear to be educated professionals. Addiction is at an all-time high. Many of the counselors were recovering addicts and their salaries don't compensate them for their skillsets. What are the guidelines for professions in this field? Most consumers don't obtain a 4-year degree and expect to pay off their college loans with an hourly wage of \$10.00/hr. In order to attract educated professionals for substance abuse therapy/counseling, we need to look at increasing the salary levels for critical care specialists in treatment centers (inpatient and outpatient).

Experiences with outpatient facilities (in particular SPHS):

- SPHS Outpatient Treatment Center, New Kensington, PA

Transportation for outpatient treatment was a huge obstacle in Kyle's case. Kyle did not have a driver's license. As a result, Kyle did not attend his appointments as expected. With no follow-up care, he would relapse. There is a need for more outpatient treatment facilities within walking distance from their

residencies or transportation needs to be addressed. Many addicts don't have a driver's license let alone a car. How can they continue with follow-up care if they can't even get there?

SPHS was the closest outpatient facility to where we lived. When Kyle was able to make his outpatient appointments (which was typically because a family member rearranged their schedule to transport him), there would be scheduling conflicts or therapists/counselors were not there to treat him. This facility didn't run like a professional doctor's office where they would notify you in advance of schedule changes. What procedures are in place when the therapist/counselor isn't there or how do they mitigate these scheduling conflicts? The employees we dealt with were less than professional at this place.

Kyle only saw a psychiatrist 1 time throughout his time at the SPHS outpatient facility. Because of this, we had to ask his PCP to prescribe his mental health medications. The PCP told us on numerous occasions that this was not his area of expertise and that Kyle really needed to be seen by a psychiatrist to be able to regulate and monitor his medications for his mental health issues. I spent countless hours trying to find a psychiatrist that would see Kyle. For the most part, when we did get a chance to speak to someone about psychiatric care for Kyle, I was told he needed to remain clean for a minimum of 1 year before he could be seen by the doctor. In my opinion, people with other diseases would be seen by a specialist without being denied treatment because of another illness. Why are addicts treated differently?

Kyle was fortunate enough to have a family that was willing and very capable to help guide him through his recovery treatment. I could never imagine if Kyle was alone, like many young adults with the same substance abuse disorder, how we would have been able to manage this follow-up care on his own. Kyle didn't have life skills, so we were left to struggle finding appropriate treatment for him on a minute's notice. This could have been a full-time job for any of us. Again, having a case work would benefit the patient.

Again, we had excellent private health care coverage through my company. As a result of mass confusion between treatment & residential facilities, we were always instructed to obtain state funding and to exhaust all state medical benefits because it was less complicated for the inpatient professionals to navigate the "system". This was because most of the patients they dealt with were on state funding insurance and that's what the facility was familiar with. They were unable or unwilling to circumnavigate the private insurance system. Why would I want my child to have state funded insurance when we already had private insurance?

Experiences with Residential Housing (specifically ¾ houses):

- Perrysville House - Pittsburgh, PA
- Rochester House – Rochester, PA
- Baden House – Baden, PA
- Tom Rutter House - Alipuiippa, PA
 - This was the only ½ way house Kyle resided at for 2 weeks. My only complaint was that they did not accept my private insurance. This is when they instructed him to obtain state funded insurance. So basically he was receiving state funded insurance which he really didn't need. Private insurances should cover ½ way housing because it is a more structured environment and appears to be regulated as opposed to ¾ housing.

We typically had to find 3/4 houses by surfing the web. When doing this there wasn't any information about the housing. No 'grade' like you would see if you were searching for a doctor. We were just

basically selecting housing 'blindly'. Who does that? As parents we wanted the best environment for Kyle so that he could thrive and continue with his long-term recovery.

The ¾ houses we dealt with were unregulated and there was no oversight of housing management or housing ownership. Anybody who can purchase or acquire a mortgage can start a ¾ house. What credentials does a person need to create a ¾ house? Who oversees that these consumers aren't taking advantage of recovering addicts?

When transitioning from a ½ way house to a ¾ house, there is a high probability of relapse due to moving from a highly regulated and structured atmosphere to "basically a free-for-all". There should be some transition policy for a recovering addict, so they can continue to progress with their recovery.

All of the facilities Kyle stayed were rampant with drug use despite the owners/managers claims that random drug testing was required.

Monthly rent at all of the ¾ houses was averaged from \$400 to \$475 per month. There were no less than 8 residents in the houses at a time. These owners/managers were receiving \$3200 per month, at a minimum, for extreme substandard living conditions. The rent paid for a roof over your head, a bed and utilities. This does not include food, hot water, cable, emergency phone line or doors that locked. Kyle was fortunate enough to have been afforded nice possessions which often "disappeared".

If Kyle ran out of money, he was forced to turn over his food stamps card to the house owner and he could get it back for 50 cents on the dollar. That's highway robbery!

Two of the ¾ houses had beds in the basement with no access to the outside. What if there was a fire in the basement? How would they escape? This had to be a violation.

The houses would put as many beds in a room they could fit and the furniture was typically busted and repaired and was filthy. We always carried our cleaning supplies to ensure his sleeping area was habitable.

Experiences with physicians care:

- Avanish Aggarwal, MD – Neurology
- Jeffrey Lineman, MD – PCP
- Dr. Bahl – Endocrinologist
- Paul Brayer, MD – SUD
 - Early in Kyle's treatment, Dr. Brayer prescribed Suboxone to help with cravings, however Kyle abused this treatment by selling the Suboxone. Therefore, and Dr. Brayer discontinued the Suboxone and recommended the Vivitrol shot. Kyle was on the Vivitrol shot for 3 months and was successful at remaining clean until the insurance provider notified Dr. Brayer that he was not a "certified Vivitrol provider." Consequently, Kyle was taken off of Vivitrol shot and prescribed Naltrexone in pill form which left Kyle to make his decision to take or not take the pill which would permit him from getting high. This ultimately led to his death (not to mention the absence of the warm hand-off process).

Although Kyle saw these doctors stated above, none of them were able to treat his mental health condition and only Dr. Lineman and Dr. Brayer were collaborating on treatment for Kyle.

Experiences with Hospitals/Detox facilities:

- Allegheny Valley Hospital ER – For overdose treatment three separate times
- Allegheny General Hospital ER – For Overdose
- UPMC Mercy Hospital ER – For Detox
- UPMC Presbyterian Hospital ER – For overdose
- Sewickley Valley Hospital ER – For Detox
- UPMC St. Margaret's Hospital ER – Seizure activity possibly related to SUD
- Beaver County Hospital ER – For Detox
- Western Psychiatric Hospital – For Detox and Psychiatric Evaluation, Two separate times

The emergency room visits and detox facility stays were short lived and in our opinion proper assessments/evaluations were not administered. This was hours to at most 5 days. Are the employees not trained for substance abuse assessments/evaluations? If an emergency visit is due to an accident and is life threatening and a person is taken to the ER, there are procedures and policies that ambulances and healthcare professionals must follow. Why is this not the case for substance abuse patients?

Just before Kyle passed away, he overdosed for a fourth time in my mother's bathroom (this was on a Friday). Kyle was revived with Narcan by medics and transferred to Allegheny Valley Hospital ER for monitoring. We begged him to go to detox or rehab because earlier in the day, he told my sister that he wanted to be with his pap (who passed away in 2010). He said he was tired of fighting. While in the ER, he was asked by several doctors and nurses to admit himself into AVH psych for detox then to could go to a rehab facility. He refused and said he was perfectly fine and stated that his aunt had made the whole thing up about 'wanting to be with his pap'. Unfortunately, the doctors and nurses listened to him instead of his family. As a last resort, his aunts tried to have him 302'd because of his suicidal ideations, but the Judge denied the 302 on the grounds that all of his problems were due to his substance abuse disorder. Kyle was subsequently discharged that evening (Friday) from the ER without a warm handoff and tragically just two days later, he died of another drug overdose.

Lastly, just to add Insult to injury, I carried an accidental death and dismemberment policy on our family. I submitted a claim because Kyle's death was ruled as 'accidental'. MetLife is the carrier of the policy and they have denied my claim and won't payout because Kyle was found to have narcotics in his system that weren't prescribed. I truly feel like he is being discriminated against for being a drug addict. Right now our plan is to appeal the decision. If this is anything like the existing medical health system it may now become another full time job of mine.

Again, I would like to thank you for your time and allowing me to voice my opinions related to my son's substance abuse treatment. I hope my testimony will be used as a resource for the HR590 task force to identify ways to help consumers get adequate access to treatment they so well deserve.