

#322

COMPLETE

Collector: Web Link 1 (Web Link)
Started: Monday, July 22, 2019 4:37:51 PM
Last Modified: Monday, July 22, 2019 4:39:54 PM
Time Spent: 00:02:03

Page 2: About Agencies Scheduled for Study

Q1 Please share any comments, suggestions or concerns you may have about these agencies, including any observations about the way the agency shares information online. Please note your responses will be posted online and may be included in a Committee report.

Mental Health, Department of

Redacted Name - Pursuant to Committee
Standard Practice 10.4.5

Everyone at AXYS, the Association for X and Y Chromosome Variations is shocked and saddened to learn of the homicide of [REDACTED] at the hands of the Department of Mental Health. Many of our sons have Klinefelter Syndrome (KS), just as [REDACTED] did. It is terrifying to imagine our sons being suffocated under a pile of adults. KS is a genetic condition. Typical people have 46 chromosomes--23 numbered pairs of chromosomes. Those with KS have an extra X and have a 47,XXY signature. You might think you do not know anyone with KS; but chances are you do. The prevalence is estimated to be about 1 in 500 males. It is as common as red hair. Because KS does not always have distinct physical features or severe behavior issues, it is estimated that a majority of KS males are not aware of their condition and that as many as 65% remain undiagnosed in their lifetime. This is changing with the advent of new prenatal tests that can screen for genetic conditions with just a blood test. This early diagnosis allows families to enter early intervention programs offering physical therapy, educational assistance and specialty medical care, leading to better functioning adults with fewer physical and psychological challenges. Because many older people with KS did not get the early intervention, they can have a developmental and maturity level that is 6-8 years behind their chronological age. This causes them to have significant difficulties with understanding the consequences of their actions during their adolescent and young adult years which can produce very irrational decisions and negative behaviors. Since [REDACTED] had been diagnosed with KS, The Department of Mental Health professional staff should have known this. Further, men with KS almost universally have primary testicular failure. The resulting hormone imbalance typically manifests with mood disorders, anxiety, cloudy,

disorganized thinking and low energy, as well as other physiologic symptoms. Was [REDACTED] treated with the appropriate dosing of testosterone to help treat these problems? For adults with KS, finding qualified and comprehensive medical care is challenging. A 2017 study of adults with KS reported that 40% of the men had no medical follow up by a specialist even though they have a strong need for multidisciplinary clinical care. Was [REDACTED] offered care by a specialist or team well-versed in KS? We look forward to a thorough investigation of the death of [REDACTED]. We would like to see all health care professionals, especially those working in the area of mental health, trained in the symptoms and best practice treatment models for individuals with KS. We believe South Carolina could help lead initiatives to better educate all health, educational and legal professionals in the State and we would look forward in helping create programs to accomplish this. AXYS is working to raise awareness, develop effective treatment models, and improve access to support services for those with KS. To learn more please visit our website at www.genetic.org or contact us at info@genetic.org. Carol Meerschaert, Executive Director of AXYS

Page 3: There are three questions seeking general information.

Q2 What is your age?

55-64 years
old

Q3 Which best describes your current role?

Not a South Carolina resident and do not fall into any of the categories above

Q4 In which county do you live?

Do not live in South Carolina
