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Klinefelter's Syndrome

The Trials, the Tribulations, the Frustrations

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My father kept saying that these would be the best years of my life. The years of junior and senior high were going to be the best that life could be. Such concepts give Stephen King the power to inhabit the dreams of cheerleaders everywhere, and for me, not much better, for I was fat. Had I simply been fat, it would have been tolerable. But I went beyond fat. I had breasts, and everyone I knew seemed to know it. Everyone, that is, except the doctors I went to see.

The job usually took me eight hours a night, sometimes longer. The first night after the [testosterone] shots began it took me three and half hours.

Year after year, from when I was twelve until I was nineteen, every doctor said the same thing, "You're Fat. Go on a diet." I could almost read the minds of each one as I walked in their office for the first time. "Hello Tubby", was written on every scowl and grimace. And year after year, the chants at school of "You need a bra" took me lower and lower down the path of self-defeat.

It was a long first year in junior college, and now I was going to see a new doctor. Here we go again. The doctor looked at me with a concentrated expression, "You've got breasts" were his first words. I shall never forget his next line. "Those are symptoms". Over the course of the next hour, he called my mom and got permission to have a rare and costly test done. He then ordered that they do karyotype (chromosome count) on me, as well as a hormone level test and a sperm count. The test took a week, and the conclusion was not obesity. It was something totally alien to me, and apparently to all the other doctors I had seen.

What is Klinefelter's Syndrome?

In the "perfect" human genetic body, there are twenty-three pairs of chromosomes in the nuclei of every gene. However, some people have extra chromosomes that cause frightening and staggering changes to them, which are most noticeable at birth. Down syndrome is probably the most famous. But in Klinefelter's Syndrome, a boy is born with male effects and female defects. What I mean, is that with a child before puberty you would never know that a Klinefelter's Syndrome boy was any different than a "real boy". That is, until puberty.

In the course of puberty, a lot of changes happen to boys. They get muscular, grow body hair, their voice deepens, their emotions go crazy, they get more aggressive, and their genitals mature. In the course of my puberty, I got breasts and fat, had no body hair, had a high voice, stayed fairly calm, and my genitals stayed as minimally hairless and small as they ever had been.

Here is the best description I have heard on what happened to me at puberty. A Klinefelter's Syndrome body matures to a female environment. It begins producing oestrogen, and it begins saving up energy (in fat) which the body will then flush out of the system at menstruation. However, since I did not have the plumbing for a menstruation, the stored energy (fat) went nowhere (or everywhere in my system). In 7th grade, I weighed 120 pounds. Then, I began this mutated form of puberty, I gained 30 pounds every year. The 120 became 150 (8th grade) then 180 (9th), 210 (10th), 240 (11th), 270 (12th), 300 (College Freshman), and then I found a doctor who diagnosed me. But now, I must share the most staggering fact of all.

Klinefelter's Syndrome is common!

It is so common that it is found in 1 out of 500 births. But if it's so common, why do so few doctors and teachers know about it? I don't know, but this page sets the course to make people more aware of the problem.

What's the big deal? It's only breasts and fat, right?

The major problem faced by me, and every other Klinefelter's Syndrome victim, is that maturity and learning go from normal to very, very slow after puberty kicks into action. It takes energy to learn, and I didn't have any. My grades throughout Elementary School were average, and in many cases above average. But as my body began to get pumped full of oestrogen, and my muscles weakened due to a lack of Testosterone, I became lethargic and weak.

I could not keep up physically, nor could I keep up intellectually. In some things, like computers, I worked well, for I could sit in one place and learn. If I had to move around, go visit the library, do research, exercise, or make any effort at all, I was muted by a weakness that was always labelled as fat and lazy. The doctors apparently never needed to look further, for it was just easier to assume that they knew what they were doing. Show me some proof that a hormone makes a difference. After the discovery of my extra chromosome, I went to Seattle to see a leader in the field of genetic dysfunction. It was an even luckier day when it turned out he was on staff at a U.S. Department of Social and Health Services hospital in Seattle.

Dr. Alvin Paulson (now retired), who was assisted by Dr. Alvin Matsumoto (who was at the University of Washington Medical School, and is currently listed as on staff with Virginia Mason Hospital in Seattle), began me on my lifetime of hormone therapy. With them, I began a shot of testosterone every fourteen days. And from the very first day, things began to happen.

I came back from Seattle to my regular life. I had a job as a weekend night custodian at a restaurant. The job usually took me eight hours a night, sometimes longer. The first night I worked, after the shots began, it took me three and half hours. And that is how long it took every week thereafter. I actually had time to relax and do a good job instead of having to slave and do a below average job, for something was different. I had energy like I had never had before.

My lack of self-esteem was the last thing to begin changing, and so began what would turn into eighteen months of therapy with a social worker. It ended with me walking taller, and feeling a bit more intolerant towards the bullies. No one could tell me I wasn't good enough now. I just needed to prove it to the only person that needed to know: Me!

Know Yourself, Love Yourself, Change Yourself:

I began to find significant changes in myself. I was later told that these changes happen to others at puberty, but I was happy to have an opportunity to go through it all. It began with a quest for discovery. I made a list of everything I thought I ever wanted to do, but hadn't done. This included many things that still haven't done, like skydiving, but along with others, like getting some of my writing published. I still upgrade the list from time to time.

Once I began to see things that I felt I was proficient enough to learn, I gorged myself in knowledge. My parents had a one-hour photo machine in their real estate appraisal business for which I worked and I dabbled in photography. I also dipped into fireworks, hypnosis, journalistic writing and poetry. But in the end, like the friend that never leaves, I found myself in computers. Through the actions of myself, and the encouraging words of others, I gained confidence, which helped my self-esteem: jack-of-all-trades, but master in six.

I am still working to get a Pyrotechnicians' License. It interests me mostly in being able to set off the fireworks even after they got outlawed, and then to get paid as well. But I am well read in explosives, though I hardly recommend anyone to go beyond knowledge these days. Still, it is a challenge to simply make gunpowder from scratch that doesn't fizzle.

My Grades and My Studies:

A big problem with my mind is that it seems to have a singular focal point. I can only concentrate on one problem at a time, though the complexity of the problem can be immense. But if I am writing a document, such as I am at this moment, I have also the focus to ignore anything that is off topic, for I think in tangent logic. If something else gets my interest, it takes a lot of effort to return to the initial task and complete it, for my interest and curiosity has shifted elsewhere. To put it in better words, a friend once said that I speak in parenthesis.

This is a major problem with the way classes exist in most schools. You take five classes, and you get fifteen hours a week to variety to keep on track. I just cannot do it. On the other hand, when a class presents itself to five days of eight hours a day and then a test on Saturday, I excel.

Looking back, my grades in Junior High and Senior High reflect slowness. In fact, I never used drugs in either school (I discovered Pot in College), but my G.P.A. went 2.0, 1.9, 1.8, 1.7 and then I had my last semester, which had my one and only "A" in High School and that was from a computer class.

College was a bit easier for a time when they allowed Z's. If you got a Z, it didn't count against you like an F did. So, being logical, I figured that by mind-term, if I didn't have an A, B, or C, I would withdraw from the class, and it wouldn't hurt me. This, combined with a computer error in my favour, which the Junior college said they could or would not fix, and so I should just shut up and accept it (a three credit hour "A" was recorded as a fifteen credit hour "A". resulting in sixty credit points). I turned my 1.6 G.P.A. into a 2.83 G.P.A., and allowed me to be accepted by Washington State University.

Maturity is built not on age, but on experience and responsibility. When I went to W.S.U., I had achieved not much of either. I could not play the petty game with grades as I did in junior college, and I discovered something even more difficult. The school was built on a mountain top, and I was in no condition to climb that many steps. I learned a lot at W.S.U., but not by going to classes. I learned a lot about people. I learned a lot about strata of societies. I learned a lot about the importance of others in my life, as well as the importance of my time alone. It was a much needed break from living at home, and I enjoyed my year away, but I still had a lot to learn about life and responsibility.

The next year, I returned home to work for the family computer business, and then enter appraising real estate.

In late 1984, my parents bought a house, and I moved into it. I began learning about responsibilities, but at times, I just could not handle it. I basically learned to pay people to help me for I could not cope with the awesome responsibilities that living alone required. My maturity levels continued to increase slowly, but they took an incredible leap in 1987, when I met the first woman who ever was interested in me.

I had been shopping for a mate with children. The sperm count that was taken all those years ago had come up empty. Not even one sperm, dead or alive, was found in the sample. So it became clear that the easiest way to get children, was to find some that already existed.

Jennifer had met me once before, and as I had bombarded her with a bunch of questions, she put me down as a pest. But when I learned that her mother was in hospital, I took her mom some books on tape to listen while there and she called her daughter to come by "now!" with a tape recorder. Jen's look on her face wasn't good when she came through the door, but once we started talking, we

never stopped. We've been married seven years now, having pulled her through hell, and she's still a special gal.

So what's the point?

I have written this article to express the life I have lived, and what has happened to me, in a nutshell, from puberty to affinity. The key to this article is if you see someone with any of the following symptoms, you may want to see them get to a doctor that will check them for Klinefelter's Syndrome and then take care to see that their dosages are well monitored.

The Symptoms

After puberty: Arm span exceeds height by more than an inch; No or very little body hair and no facial hair; High voice; Minimal muscle growth in arms/legs; Weak or no energy; Small testicles; Breast Tissue (not just fat, but actually firm breasts); Low Testosterone level; High oestrogen level; Karyotype reveals XXY sex chromosomes.

What other Klinefelter's victims have done

One time on Prodigy, I asked around for Klinefelter's Syndrome'ers and found about ten. Half of these had said that they had sex change operations. One of the men left said he had had no shots or therapy ever and is in his fifties. Most Klinefelter's Syndrome people have had sex with someone of their same gender during puberty. Studies I have seen shown that 80 percent of all boys experience something along this line, but only 10 percent of the population appears to be "gay". There does not appear to be any defined indication if any of the 20 percent that did not have a gay experience ended up gay.

All Klinefelter's Syndrome people appear to get lethargic after puberty, and have a difficult time learning, but all of them said computers were a snap, or something of interest. The guy who said he was in his fifties, also mentioned that his parents were doctors, his siblings were doctors, and he is the only one that is committed just to computers, but did not do well in school, for he couldn't concentrate that well.

So is that all?

Well, actually, this is the start. From here, we need to find out what can be done for the others to recognise that Klinefelter's Syndrome people are not given an easy hand, and that they may need more learning opportunities or boosts. It may take a little longer to get anywhere, but with therapy and a little help, the work should be worth it.

Information of Klinefelter Syndrome

Klinefelter Syndrome is probably the most common chromosomal variation found in humans. In random surveys, it is found to appear about 1 in every 500 to one in every 1,000 live born males. Since the largest percentage of these men would have never been diagnosed otherwise, it shows that in many cases affected individuals lead healthy, normal lives with no particular medical or social questions. Klinefelter Syndrome is diagnosed through a karyotype; a chromosome analysis usually done on a blood sample.

Klinefelter Syndrome is caused by a chromosome variation involving the sex chromosomes. While Dr. Harry Klinefelter accurately described this condition in 1942, it was not until 1956 that other researchers reported that many boys with this description had 47 chromosomes in each cell of their bodies instead of the usual number of 46. This extra sex (X) chromosome causes the distinctive make-up of these boys. All men have one X chromosome and one Y chromosome, but sometimes a variation will result in a male with an extra X. This is Klinefelter Syndrome and is often written as 47XXY.

Common Characteristics

The most common conditions that males with Klinefelter Syndrome may have are sterility, breast development, incomplete masculine body build, and social and/or school learning problems. The most common characteristic of men with Klinefelter Syndrome is sterility.

Frequently, adolescent boys with Klinefelter Syndrome may undergo some breast tissue development. In some cases, this may necessitate surgical removal of the breast tissue.

Although most boys with Klinefelter Syndrome are tall (the average is 6ft½in.), they may not be particularly athletic or coordinated. The penis is usually of average length, although the testes are small. There may be a decreased growth of facial hair. Studies indicate an increased risk of speech and language problems which contribute to social and/or school learning problems. Boys with Klinefelter Syndrome may be more immature, shy and dependent than their brothers and other boys their age. They may be somewhat passive and apathetic; they may lack initiative, be very sensitive, and have a fragile self-esteem.

Treatment

The most common form of treatment involves administering Depo-Testosterone, a synthetic form of testosterone, by injection once a month. The dose gradually needs to be increased and given more frequently as the boys get older.

Health.

The Gender Centre is committed to developing and providing services and activities, which enhance the ability of people with gender issues to make informed choices. We offer a wide range of services to people with gender issues, their partners, family members and friends in New South Wales. We are an accommodation service and also act as an education, support, training and referral resource centre to other organisations and service providers. The Gender Centre is committed to educating the public and service providers about the needs of people with gender issues. We specifically aim to provide a high quality service, which acknowledges human rights and ensures respect and confidentiality.