

CUMC Study Explanation



KS is a condition that, in the past, was primarily identified in early adulthood or late adolescence. Men with KS are known to have health problems and risks that are associated with the testicular failure that goes along with KS. Now that boys are being identified earlier from birth or before the age of puberty, we can see that boys with KS may (or may not) have early signs of physical, neuro-cognitive and social issues that affect them throughout their lifespan. Early identification of issues or problems provides the opportunity to intervene earlier in life.

One of the problems with understanding KS in childhood is that there is very little research done with boys. Most of the past research has been done on men in their 20's-60's. KS has also been neglected by the research community because clinicians and many researchers have never had the experience of working with KS individuals. Without active research, it is extremely difficult to generate additional interest and funding for further investigation of KS. At the moment, there is no clinical guideline that advises clinicians how to evaluate or treat adults or children with KS. This is why there is only anecdotal information on when, why and how to treat with testosterone replacement and what features of KS it really helps.

The overarching goal of our research is to provide a deep and thorough description of boys with KS during the peri-pubertal

years to provide a solid foundation for the next generation of research questions concerning the best way to provide positive interventions for health. Dr. Fennoy and I just reported early bone mineral density findings that suggest there is bone loss (as in the very early development of osteoporosis) during late adolescence.

The CUMC study involves a physical exam and answering questionnaires on quality of life, self-esteem, self-concept and depression. Lab order sheet will be given to parents to have your child's blood drawn via your local LabCorp. All blood work will be paid by the study.

The blood studies are to assess reproductive hormones and heart, bone and fat biomarkers. About 5 tsp of blood will be taken for the blood analysis. The blood will be sent to a special lab in California that has special assays that detect "Pediatric" levels.

The questionnaires are pencil and paper-type, most asking yes/no questions or to rate something on a scale from 1-3 or 1-5.

We are specifically looking at the physical characteristics of the boys as they develop, whether they have evidence of early metabolic problems like insulin resistance, the status of their bone development, and how they feel about their lives.

We are funded for the study for the cost of the assays and blood work. All of the work-up would be without cost to you. Your son will receive a \$25 American Express gift card for his time.