



# KALEIDOSCOPE

THE AMERICAN ASSOCIATION FOR KLINEFELTER SYNDROME INFORMATION AND SUPPORT



2002  
Vol. 3 Number 1

## Issue Focus—Testosterone

### The Patient's Guide to Low Testosterone

by The Hormone Foundation



#### Preface

It is estimated that 4 million to 5 million American men may not produce enough testosterone. Most discouraging, research finds that most men know very little about testosterone, the potential consequences of having low testosterone levels, and the availability of therapies to increase testosterone and overall health.

*A 1998 survey completed by Roper Starch Worldwide of 1,000 men found that 68 percent of participants could not name a symptom or condition associated with low testosterone. In addition, half of the participants admitted some knowledge of hormone replacement therapy, but only 7 percent knew that it could be used in men.*

This guide seeks to improve your awareness of testosterone, testosterone deficiency, and testosterone replacement therapy. Section 1, *Testosterone Overview*, provides comprehensive information on the hormone, its function, the diagnosis of low testosterone, and other related factors. Section 2, *Benefits of Testosterone Replacement Therapy (TRT)* discusses some of the physical and psychological benefits associated with restoring testosterone. Section 3, *Treatments for Low Testosterone*, outlines treatment options that are available to increase testosterone levels. Section 4, *Overview of Clinical Trials*, presents highlights of recent clinical studies evaluating testosterone and testosterone replacement therapy. Finally, Section 5, *Frequently Asked Questions*; Section 6, *Glossary of Terms*; and the Appendix will provide you with additional educational information.

This guide provides useful information on testosterone and testosterone therapy. In addition, it creates a foundation for increasing your knowledge of these important topics.

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### ..... from the President



AAKSIS has come a long way from its start-up in the Spring of 2000. Following its first national conference held in Chicago in 2000, the organization sponsored a second national meeting in Philadelphia this past August. In attendance were individuals, families, and educational, psychological and medical professionals who had never been to an educational event centering on Klinefelter Syndrome. The conference set the stage for AAKSIS to continue to expand its educational and support role. For the coming year, we plan to increase our visibility within the XXY community and to the professionals who serve it.

A highlight of the conference was the *AAKSIS Lifetime Achievement Award* given to journalist, Robert Bock. As a press officer with the National Institutes of Health, he authored the booklet, "Understanding Klinefelter Syndrome". His account described the condition in a more accurate and optimistic way for both the medical and lay community.

Carole Samango Sprouse opened the convention with her overview of the impact of XXY on the development of the young child. Mary Davidson, an AAKSIS Board member, gave a second keynote presentation on the *Peoples Genome Celebration*, highlighting the promise of research into genetics and perils of failure to protect the confidentiality of an individual's genetic findings. The workshops included presentations by Drs. Wolfram Nolten, Arturo Rollo, and William Zipf on adult and pediatric endocrinology issues. Psychologist, Dr. Daniel Davis gave insight into child and adolescent behavior, particularly in XXY's and plastic surgeon, Dr. Robert Bermant, described state-of-the-art surgical procedure for gynecomastia. The program also included presentations by speech pathologist, Tammy Weaver, who focused on therapy in the young child. Board member, Dan Becker, explained fertility options for this community. Sunday opened with a joint presentation by NIH neuropsychiatrist, Jay Giedd and psychiatrist Jefferson Prince, who discussed brain imaging studies of XXY and ADHD populations as well as medication issues. A full panel of specialists was on hand for a question and answer session. The conference ended on a light note with a presentation by Lois Walden, R.N., who entertained us with a humorous look at stress in our lives. We give special recognition to Dr. Nolten who provided consultations throughout the conference, adding as many "slots" as necessary to fill the requests. We thank him for his generous contribution.

**Looking to the future**--Klinefelter Syndrome must become a recognizable condition so that diagnosis can be made early, allowing for appropriate treatment and educational interventions. The challenge for AAKSIS is to communicate our message to a wider community. We cannot be satisfied with just educating ourselves. We must reach genetic counselors, physicians, teachers, psychologists, and psychiatrists, as well as diagnosed individuals and families. We need to make medical specialists as well as family practitioners, internists, and pediatricians aware that accurate information is available upon request and that AAKSIS volunteers are prepared to offer support to the newly diagnosed.

Fund-raising and grant writing are priorities for the coming year so that AAKSIS can begin to "blanket" regions with educational information and publicity materials, attend and staff displays at professional conferences, and provide speakers for the medical and educational communities. A few individuals cannot do this alone. We need your involvement as a volunteer. Please consider a commitment. Any contribution, great or small, will move all of us toward our mission of early identification and appropriate medical interventions. Help us remove the myths and misunderstandings that have been with us far too long.

Ginnie Cover



AAKSIS toll free hotline  
(888) 466-KSIS (5747)



AAKSIS Website  
[www.aaksis.org](http://www.aaksis.org)

### AAKSIS Medical Advisory Board Adds New Member

Dr. Jefferson Prince, director of Child and Adolescent Psychiatry at the North Shore Medical Center in Salem, Massachusetts and staff member of the Child Psychiatry Clinic at Massachusetts General Hospital is now a member of the AAKSIS Medical Advisory Board.

Dr. Prince is a widely published author and lecturer in the field of psychiatry as well as an instructor in psychiatry at the Harvard Medical School. His areas of research and interests are the characterization of ADHD, anxiety, depression, and bipolar disorders in children, adolescents, and adults; substance abuse in children and adolescents; and the delivery of psychiatric services in the health care system.

**KaleidoScope** is a publication of AAKSIS,  
The American Association for Klinefelter  
Syndrome  
Information and Support.

**KaleidoScope** is published three times a year  
and is free to members of AAKSIS.

Articles in this newsletter may not be  
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