

## SUMMARIES

### **Lecture: Living with CAH: Issues of Gender and Romance for Women (Heino Meyer-Bahlburg, Ph.D.)**

Girls and women with CAH do remarkably well overall. Yet, some may need to cope with a number of challenges beyond their medication schedule.

When untreated, and starting well before birth, CAH is associated with underproduction of cortisol (and, in some women, aldosterone) and overproduction of androgens. After birth, cortisol-replacement treatment aims at the optimal balance between both, which is difficult to achieve. Both overproduction and underproduction of these hormones may have visible effects on the body, for instance on overall body built, weight, body hair, skin (acne), genital features. How strong the effects are depends on the genetic type of the CAH condition, the fine-tuning of the hormone replacement therapy, and the quality of genital surgery, if applicable. Some girls and women with CAH become very self-conscious about body effects, especially in a culture that exposes everyone to unrealistic demands for feminine appearance embodied by highly selected advertising models for body-care products and procedures.

The excess production of androgens, especially during very early developmental stages (fetal life), may also influence temperament, toy and game activities in childhood, leisure-time interests in adolescence and later, and occupational choice. If these psychological effects are strong, some adolescents may even develop self-doubts about their female gender, but for most of those, such doubts only constitute a transient phase.

The effects on body and behavior may influence with whom in the peer group one likes to hang out. Self-doubts about their femininity may slow girls and women down in entering the scene of dating and romance. Some may have been exposed to other people's curiosity about their medical condition or even to teasing and derogatory remarks, which may inhibit them socially. A related sensitive issue is whom one tells what about one's medical condition, and at what point in the relationship.

Based on the speaker's clinical experience and own research as well as on reports by others, this talk will describe some of the relevant psychological findings.

### **Break-out session: Challenges of Living as a Woman with CAH (facilitator: Heino Meyer-Bahlburg, Ph.D.)**

In following up on the lecture, the goal of the break-out session is to have women with CAH (and perhaps parents of adolescents with CAH) share with each other their CAH-related concerns and experiences (in the case of parents, their adolescents' experiences) in these and other areas of life, and, especially, what they found to be the best way of dealing with them.

**Break-out session: Talking with Your Daughter about Surgery (facilitators: Richard Rink, M.D.; Louise Fleming, Ph.D., R.N.; Heino Meyer-Bahlburg, Ph.D.)**

The topic of genital surgery is particularly sensitive, because it raises questions about the function of the genitals, sex differences, sexuality, fertility, and the causes of atypical formation of the genital structures; in addition, the timing of genital surgery is currently controversial. When and how parents and daughters talk about genital surgery depends on many factors: for instance, genital appearance and status, plans for future surgery, past surgery, daughter's age and cognitive development, family's style of dealing with sexual matters, and daughter's experience with others' curiosity and comments. The goal of this break-out session is to have parents of girls with CAH (and perhaps also some women with CAH) share with each other, how they deal with talks about surgery, and to have the professionals describe the approaches they take to assist parents in this matter.

**Selected references:**

C. Y. Hsu & S. A. Rivkees: Congenital adrenal hyperplasia. A parents' guide. Author House: 2005. [For medical issues.]

<http://www.sickkids.ca/childphysiology/> – Under “How the Body Works” see the section on “Sex Development” etc.

Consortium on the Management of Disorders of Sex Differentiation: Handbook for Parents, 2006. Accessible at: <http://www.accordalliance.org/>

Meyer-Bahlburg, H. F. L. Psychoendocrinology of congenital adrenal hyperplasia. In: New, M. I., Lekarev, O., Parsa, A., Yuen, T. T., O'Malley, B., & Hammer, G. D. (Eds.), Genetic steroid disorders. London, Waltham, San Diego: Academic Press/Elsevier, pp. 285-300, 2014.