Questions about psychological adjustment have most often been asked in the context of the virilized genitalia of girls with CAH. For many years, early surgery to "normalize" the genitalia of girls with CAH was considered necessary to promote the development of normal female gender identity and overall psychological health. But now, some are suggesting that the surgery, rather than preventing problems, actually produces them. Both physical and psychological problems have been suggested to result from surgery. Physical problems might include reduced genital sensation because of damage to the nerves and blood supply to the clitoris, and pain during intercourse because of scarring from vaginal surgery. These physical problems are then suggested to result in sexual problems, such as dissatisfaction with and avoidance of sex. Although the focus of this article is not on genital or sexual function, it is important to note that there is very little good evidence about these outcomes in women with CAH. What little evidence there is shows that some women with CAH are satisfied with their sexuality and some are not, but satisfaction does not appear to be related in a simple way to the surgery that was done. Perhaps this is not surprising, given that there is a lot of variability in sexual satisfaction in women without CAH. There are other ways in which virilized genitalia might result in psychological problems in females with CAH. These include, for example, repeated genital examinations (which have been likened to sexual abuse), or shame and stigma associated with a girl's physical appearance (either with or without surgery).

Despite the abundance of speculations about the consequences of being born with virilized genitalia and having surgery to correct them, there has been surprisingly little evidence about psychological outcome in females with CAH. A few older studies found females with CAH to have good overall psychological adjustment, but those studies need to be repeated because they did not use very good measures (so they might not have been able to detect problems), and it is not clear how well they can be generalized to girls diagnosed with CAH today.

My colleagues and I studied psychological adjustment in two groups of people with CAH. Joining me in this work were Dr. Stephen Duck, a pediatric endocrinologist at Evanston Hospital in Illinois, Susan Resnick, a psychologist at the National Institute on Aging, and Kristina Bryk, a social worker and research assistant who has worked with me for many years and who conducts most of the home testing visits. The study participants were also key collaborators in this work.

The first group of participants we studied includes boys and girls with CAH and

their unaffected siblings who participate in our ongoing longitudinal study. (Other published results from this group show females with CAH to have higher spatial ability than their sisters without CAH.) We measured psychological adjustment with widely-used and accepted measures. In the first group, parents reported on their children's behavior, and teenagers reported on their own feelings and behavior. In the second group, all participants reported on their own feelings and behavior.

Results from both groups show that individuals with CAH have good adjustment. This applies to females and males with CAH, in childhood, adolescence, and adulthood. In both groups of participants, people with CAH were not different from their siblings without CAH on the measures we used. Both patients with CAH and their siblings had scores that were similar to scores of people in the general population.

We also looked at the association between adjustment and aspects of CAH, especially details of genital appearance and surgery. We were only able to do this in the first group, relying on medical records to get this information. Dr. Duck carefully extracted information from the records about genital appearance at birth and details of medical and surgical treatment. We wondered if, as originally believed, adjustment was better in girls who had had surgery early in life or, as some now believe, that adjustment was better in girls who had later (or no) surgery. We found that adjustment was not associated with the age at which the surgery was done or with how virilized the genitalia were when the girls were born. So, it looks like it doesn't matter how old the girls were when the surgery was done, at least as far as the outcomes we measured. But, there is an important caveat to these results – most girls did have surgery early in life (the typical age at clitoral surgery was between 1 and 2 years of age, the typical age at vaginoplasty was between 2 and 4 years of age), so we could not really compare those with surgery in infancy to those with surgery in adolescence. We also were unable to examine whether other factors related to genital appearance and function might affect adjustment, so we do not know if there is an effect on adjustment of the number of surgical procedures, the quality of the surgery, or the number of genital examinations. So, we do advocate more studies to explore the association between psychological adjustment and genital virilization or surgery.

Our findings of good psychological adjustment in patients with CAH might be surprising given complaints from intersex activists and assumptions about the consequences of having CAH or an intersex condition or any chronic illness. But,

intersex activists are probably not representative of the population of individuals with intersex conditions, particularly CAH. Further, there's quite a lot of scientific evidence that shows that unfortunate life events (such as cancer and spinal-cord accidents) have only temporary effects on adjustment. (It's also true that really pleasant events, such as winning the lottery, often have short-lasting effects). It's also true that people are not very good at predicting what will make them (or others) happy, because they attend only to causes that are right in front of them and ignore other factors that might be relevant.

So, what do our results mean for you and your family? They mean that CAH and its treatment are not generally a cause of psychological problems. They also suggest that genital appearance and age at surgery are not big contributors to adjustment in girls and women with CAH, but, again, we note that we have only begun to look at this. We also emphasize that we only looked at broad indicators of adjustment. It may turn out that females with CAH have problems in specific areas, such as body image, or that both males and females with CAH are more responsive to stress than those without CAH. We are currently exploring these possibilities. This means that you can expect your child with CAH to be pretty similar to your children without CAH in overall adjustment. Of course, there are some people with CAH who do have psychological problems, just as there are people without CAH who have problems. And it may turn out that CAH causes problems for people who are reactive, but if they didn't have CAH, then something else might trigger their problems. But problems do not appear to be more common in CAH than in the general population. Nevertheless, if your child does have a problem, don't ignore it – there are many good health professionals and treatments available to help you and your child.