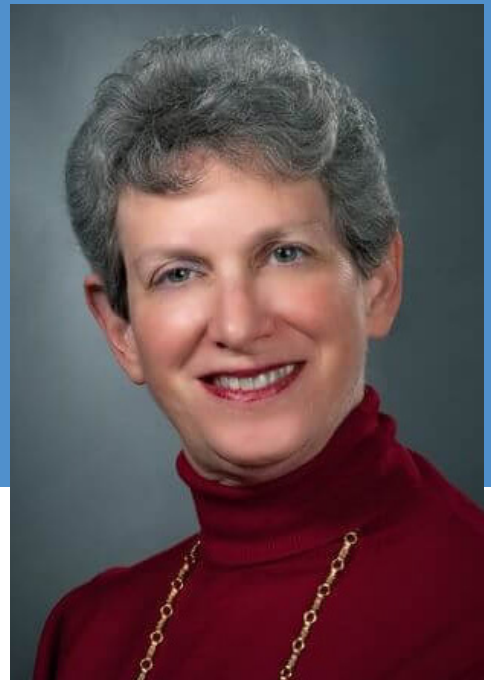


Q&A:



Phyllis W. Speiser, MD

***Endocrine News* talks with Phyllis W. Speiser, MD, chair of the task force that created the latest Endocrine Society Clinical Practice Guideline on congenital adrenal hyperplasia.**

In September, the Endocrine Society issued a clinical practice guideline on treating patients with congenital adrenal hyperplasia. Titled “Congenital Adrenal Hyperplasia Due to Steroid 21-hydroxylase Deficiency: An Endocrine Society Clinical Practice Guideline,” this is an update to the previous guideline on this topic, which the Society published in 2010. The updated guideline was published online September 27 and will appear in the November 2018 print issue of *The Journal of Clinical Endocrinology & Metabolism*.

Phyllis W. Speiser, MD, from the Cohen Children’s Medical Center of New York and Northwell Health, is the chair of the writing committee that authored the guideline. She shared her thoughts with *Endocrine News* about how she hopes this guideline will aid healthcare professionals who treat patients with congenital adrenal hyperplasia (CAH) as well as prove to be a vital resource for those in other specialties.

ENDOCRINE NEWS: What was the main reason for the publication of the CAH guideline – what drove the decision and why now?

PHYLLIS W. SPEISER: CAH is among the more common inherited endocrine disorders. The Endocrine Society felt it was important to update the previous guideline to reflect newer published data and refresh our thinking on this subject. One example is the accumulating evidence that there are potential serious long-term adverse effects of dexamethasone given in utero. Others include prospects of advanced reproductive techniques, such as pre-implantation genetic diagnosis and non-invasive prenatal diagnosis in managing pregnancies at risk for CAH.

EN: What are your hopes for the impact of the guideline on endocrine standards of care for congenital adrenal hyperplasia?

PWS: Our writing committee hopes that healthcare professionals who treat people affected with CAH will use this guideline as a key resource for best practices and in planning management of individual patients. We are concerned about the lack of care continuity between the pediatric and

“We are concerned about the lack of care continuity between the pediatric and adult age groups and expect this guideline will clarify the need for ongoing care throughout the life cycle.”




“We feel strongly that the approach to the medical, surgical and psychological management of CAH should involve carefully considered shared decisions among families, their healthcare teams, and support groups. Management should be individualized, based on expert opinion supported by the strongest available evidence.”

adult age groups, and expect this guideline will clarify the need for ongoing care throughout the life cycle.

EN: How do you expect other medical specialties to be affected by the Guideline Writing Committee's recommendations?

PWS: Besides endocrinologists, an individual with CAH over a lifetime will probably consult with multiple specialists, including geneticists, urologists, gynecologists, obstetricians, reproductive endocrinologists, and mental health professionals. We've tried to incorporate recommendations covering the gamut of these disciplines.

EN: What are the key take home messages for patients in this guideline?

PWS: The key take home messages of our CAH guideline are: The need for prompt and accurate diagnosis of classic CAH in newborns, ongoing vigilance to ensure normal growth and puberty, and establishing continuity of care in adult life. The lay public and the medical community should be made aware that CAH is distinct from other differences in sex differentiation. We feel strongly that the approach to the medical, surgical and psychological management of CAH should involve carefully considered shared decisions among families, their healthcare teams, and support groups. Management should be individualized, based on expert opinion supported by the strongest available evidence. 

This guideline is co-sponsored by the CARES Foundation, European Society of Endocrinology, European Society for Paediatric Endocrinology, Societies for Pediatric Urology, and the Pediatric Endocrine Society

Aside from Speiser, other members of the guideline-writing task force included: Wiebke Arlt, University of Birmingham, Birmingham, UK; Richard J. Auchus, University of Michigan, Ann Arbor; Laurence S. Baskin, University of California San Francisco and UCFS Benioff Children Hospital, San Francisco; Gerard S. Conway, University College London Hospitals, London, UK; Deborah P. Merke, National Institutes of Health Clinical Center and The Eunice Kennedy Shriver National Institute of Child Health and Human Development, Bethesda, Md.; Heino F. L. Meyer-Bahlburg, New York State Psychiatric Institute and Columbia University, New York; Walter L. Miller, University of California San Francisco and UCFS Benioff Children Hospital, San Francisco; M. Hassan Murad, Mayo Clinic Evidence-based Practice Center, Rochester, Minn.; Sharon E. Oberfield, Columbia University and New York-Presbyterian, New York; and Perrin C. White, University of Texas Southwestern Medical Center, Dallas.