

JUNE 2014 NEWSLETTER

TRANSITION FROM PEDIATRIC TO ADULT CARE FOR GIRLS DIAGNOSED WITH ADOLESCENT PCOS

The June newsletter is dedicated to the issues related to the transition from pediatric to adult care in girls diagnosed with adolescent PCOS. Professor Ellen Connor interviewed Selma Witchel, M.D.. Selma has been President of AEPCOS Society and is an Associate Professor with Tenure and the fellowship director of the Pediatric Endocrinology Fellowship Program of Children's Hospital of Pittsburgh of UPMC. She has published and spoken extensively in the field of adrenal steroidogenesis, and has particular interest in adolescent polycystic ovary syndrome. She is a committed and eloquent advocate for well-planned transition of the girl with suspected or confirmed PCOS.

In this issue we welcome ANSH LABS as Gold Corporate member of AEPCOS Society.

Our Society has also decided to give a scientific support to an important PCOS women group, PCOS challenge group.

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FORTHCOMING AEPCOS MEETINGS

- 12th Annual Meeting of Androgen Excess & PCOS Society, Kauai Marriott Resort Hotel and Beach Club, Kauai, Hawaii, USA, October 22-23, 2014
- Update Meeting of AEPCOS Society, San Diego, CA, USA, March 4, 2015
- Update Meeting of AEPCOS Society, Gdansk, Poland, June 12-13, 2015
- 13th Annual Meeting of AEPCOS Society, Palermo, Italy, October 4-6, 2015

12TH AEPCOS ANNUAL MEETING, KAUAI, HAWAII, OCTOBER 22-23, 2014

The 12th Annual meeting of the AEPCOS Society will be held at Kauai Marriott Resort Hotel and Beach Club, Kalapaki Beach, Kauai, Hawaii, USA, October 22-23, 2014, immediately after the Honolulu ASRM Annual Meeting. The venue of next annual meeting is a wonderful resort that is located in the very beautiful island of Kauai. The airport of Lihue, only one mile from the resort, may be reached by a



short 20 minutes flight from Honolulu. Several airlines serve this route with more than 10 daily flights. Lihue airport may be reached also by daily direct flights leaving from main Western USA and Canada cities including Los Angeles, San Francisco, Phoenix, Seattle and Vancouver. We have negotiated a very good rate at the Kauai Marriott that will be available to all registered guests for the duration of the meeting and for the following three days. Resort fee is optional but registration includes free shuttle bus from the airport. **As a special bonus for pre-registered (before October 1, 2014) AEPCOS and ASRM members attending ASRM meeting, we will reimburse \$100 of the Honolulu-Lihue flight price (actual cost of the return ticket is \$103). AEPCOS members flying directly to Lihue from continental USA will get \$50 reimburse.** Abstract deadline is August 31, 2014 and in next few weeks abstract form will be available.

CME points have been requested and should be available for attending doctors.

ABSTRACT SUBMISSION FOR 12TH AEPCOS ANNUAL MEETING

You are invited to submit abstracts of your original research to be considered for presentation at the 12th Annual Meeting of the Androgen Excess & Polycystic Ovary Syndrome Society. For abstract form, connect to: www.ae-society.org or contact: info@ae-society.org

To be considered for presentation your abstract must be submitted no later than September 7th, 2014, 11:00 pm (2300 hrs.) PST. All abstracts must be submitted by email in word to: info@ae-society.org. The presenter is required to register for 12th Annual Meeting of the AE-PCOS Society on submission of the abstract

All abstracts will be reviewed by a blinded scientific committee nominated by AE-PCOS Annual Meeting Committee. Accepted abstracts will be published on the abstract book and presented as oral communications.

The Baumgartner-Azziz AE-PCOS fund will award 2 Travel Awards (\$750 each) to the best abstracts presented by young (<35 years) investigators.

AEPCOS SPONSORED MEETINGS

- PCOS Challenge PCOS Awareness Symposium, September 21, 2014, Lake Lanier Islands Resort, GA, USA

OTHER MEETINGS

- European Society for Pediatric Endocrinology: September 18-20, 2014, Dublin, Ireland
- ASRM: October 20-22, 2014, Honolulu, HI, USA
- 12th Annual World Congress on Insulin Resistance Diabetes and Cardiovascular Disease: November 20-22, 2014, Sheraton Hotel Universal City, Los Angeles, CA, USA
- Endocrine Society, March 5-8, 2015, San Diego, CA, USA

AGREEMENT BETWEEN AEPCOS SOCIETY AND PCOS CHALLENGE GROUP

PCOS Challenge Group is a PCOS awareness group that includes about 22,000 women with the disorder. This patient group organizes several activities for women with PCOS including recreational and scientific activities.

An agreement was recently reached between PCOS Challenge Group and AEPCOS Society with the objective to give a scientific support to the activities of PCOS Challenge Group. As part of this agreement a special AEPCOS Committee chaired by Ricardo Azziz and formed also by David Abbott, Tracy Bekx, Shahab Minassian and Walter Futterweit will take care of organizing a scientific session at the PCOS Challenge PCOS Awareness weekend that will be held next September 20-21 in Lake Lanier Islands Resort, GA, USA.

For all information regarding the activities of PCOS Challenge Group and the meeting sponsored by AEPCOS, please contact Sacha Ottey: info@pcoschallenge.com or consult www.pcoschallenge.com

ANSH LABS BECOME GOLD CORPORATE MEMBER OF AEPCOS SOCIETY

ANSH LABS is a company that is based in Webster, TX, USA and that was founded few years ago by some people that previously worked in DSL diagnostics. In June, ANSH LABS became a gold corporate member of AEPCOS Society. ANSH LABS is specialized in producing some quality commercial assays for laboratory use and, in particular, AMH assays. Because there is a need of new, reliable AMH assays, the editor has asked to the director of sales and marketing of ANSH LABS to present their AMH assays.

*Ansh Labs has two AMH assays for research depending on the sensitivity required: Ultra-sensitive AMH ELISA and picoAMH ELISA. The Ultra-sensitive AMH ELISA has an analytical measurable range of 0.08-14 ng/ml and is sensitive to approximately 23 pg/ml. This assay has become a method of choice for studies of AMH in polycystic ovary syndrome (PCOS) because of its specificity, precision, and linearity of dilution. Because sensitive detection of AMH is so important in many applications, we designed our picoAMH ELISA with a range of approximately 3-750 pg/ml with analytical sensitivity down to <2 pg/ml. This assay is perfectly suited to the measurement of declining levels of AMH in studies of gonadotoxicity, oncofertility, primary ovarian insufficiency, premature ovarian aging, and menopause. Both test kits feature unparalleled specificity and sensitivity. The assays quantify the full length and non-covalent complex forms of human AMH and do not exhibit cross reactivity to other species AMH, different conformations of AMH, or other TGF-Beta superfamily hormones. Additionally, we have stabilized the recombinant human associated form of AMH and use this protein in the calibrators and controls included with the reagent kits. The Ansh Labs assays do not exhibit interference by factors such as complement, heterophilic antibodies, or conformational changes in epitopes of the AMH protein due to sample handling conditions. (Anthony M. Morrison)
Director Sales and Marketing*

**ANDROGEN
EXCESS &
PCOS SOCIETY**

12520 Magnolia Boulevard,
North Hollywood,
CA 91607, USA

Email :
info@ae-society.org

www.ae-society.org



Selma Witchel, M.D.

ADOLESCENT PCOS: PROBLEMS IN TRANSITION TO ADULT TREATMENT

This month's newsletter interview was conducted with AE-PCOS Past President Selma Feldman Witchel. Her recent commentary in the Journal of Clinical Endocrinology & Metabolism is a call to pediatric, adult, and reproductive endocrinologists to provide appropriate and timely healthcare, coordinate a transition process which includes thorough patient education, and identify adult colleagues to continue evaluations and management after the transition process is completed.

DOKRAS A, WITCHEL SF. : ARE YOUNG ADULT WOMEN WITH POLYCYSTIC OVARY SYNDROME SLIPPING THROUGH THE CRACKS? J CLIN ENDOCRINOL METAB 2014; 99(5):1583-1585

1. Dr. Witchel, how did your interest in PCOS arise?

I became a pediatric endocrinologist after being fascinated with endocrine physiology during my pediatrics residency in Cincinnati when I worked with Mark Sperling who was chief of pediatric endocrinology at the Children's Hospital Medical Center at the University of Cincinnati. During my pediatric endocrinology fellowship, I worked with Peter Lee, who was interested in congenital adrenal hyperplasia, precocious puberty, and gonadal development. In this "steroid" filled environment, my interest in the pathophysiology and genetics of polycystic ovary syndrome was nurtured. The complexity and physiology of this heterogeneous disorder continues to fascinate me.

2. What programs/education do you provide (in Pittsburgh) for adolescents who have symptoms or diagnoses potentially consistent with PCOS?

We talk about physiology of the reproductive axis, so they have some sense of what is making us consider the diagnosis of PCOS, and possible treatments. Because so many adolescent girls who present with clinical hyperandrogenism and irregular menses have elevated BMIs, a nutritionist is available to educate the girls and their families (usually just mothers) regarding healthy nutrition to promote wellness and weight loss. We are also fortunate to work with a health psychologist who has a particular interest in PCOS, weight loss, and the use of motivational interviewing. We also discuss hirsutism. We review treatment options for hirsutism and bemoan the fact that insurance generally does not cover the expenses of electrolysis or laser treatment for the treatment of hirsutism.

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3. *What do you see as the greatest challenges in making the diagnosis of PCOS in adolescents?*

There is no consensus on the diagnostic criteria for PCOS in adolescent girls because of the heterogeneity in the symptoms and overlap with normal adolescent physiology and pubertal development.

4. *What are the potential pitfalls that clinicians face in making an earlier vs. later diagnosis of PCOS in adolescents?*

With too early a diagnosis, there is the potential to generate anxiety in the girl and/or her mother, especially regarding the potential for infertility. In addition to this uneasiness, early and inappropriate diagnosis of PCOS can lead to potential insurance problems with mislabeling (labeling with diagnosis later determined not be present). One needs to indicate to the girl (and her mother) that she has a high risk to develop PCOS because of her symptoms and laboratory data. Her specific symptoms should be treated. Yet, at the same time, if a discussion about the risk for PCOS does not take place before the girl's transition (to college or adult care), then as Anuja Dokras described in our commentary, the girls can go off to their different "silos" and get compartmentalized care without a unifying diagnosis.¹

5. *What do you advocate in arranging transition of care for a girl with confirmed or suspected diagnosis of PCOS?*

My transition process follows them through their undergraduate education. I have ongoing discussions with both the young women and their mothers about physiology and lifestyle interventions to decrease their risk to develop diabetes mellitus and metabolic syndrome. We discuss potential fertility concerns with the reminder that they should not consider their health situation to be an adequate form of birth control.

Multi-disciplinary care is valuable because conversations among the pediatric, adult, and reproductive endocrinologists, nutritionists, psychologists, and exercise physiologists greatly benefit these emerging adults.