

APRIL NEWSLETTER: FOCUS ON PEDIATRIC ENDOCRINOLOGY

The April newsletter is dedicated to the diagnosis of PCOS during adolescence. A member of the Editorial Board, Tracy Bekx, M.D., Assistant Professor of Pediatric Endocrinology at the University of Wisconsin and Co-Director of the Adolescent PCOS Clinic, has addressed this issue, interviewing two well known experts in the field: Drs. Patricia Vuguin and Ellen Connor. Both Patricia and Ellen are members of AEPCOS Society and have worked extensively in this field.

Because the treated issues are often controversial, we encourage comments from our members and will publish these in future newsletters. If you wish, you may send a letter to: enrico.carmina@ae-society.org

In this issue, we have a letter from Michel Pugeat, Professor of Endocrinology in Lyon, France, commenting our March Newsletter topic: testosterone assay and the role of PATH.

Information regarding 11th Annual Meeting of AEPCOS Society is reported, too.

For any information about all AEPCOS meetings, you may contact: info@ae-society.org

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- * Diagnosis of PCOS during adolescence
- * Letter related to testosterone assay and the PATH role
- * 11th AEPCOS Annual Meeting

Editorial Board

- Enrico Carmina, M.D., Palermo, Italy
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- Jan McAllister, Ph.D., Hershey, PA, USA
- Poli Mara Spritzer, M.D., Porto Alegre, Brazil

FORTHCOMING AEPCOS MEETINGS

- Update on Androgen Excess Disorders, Prague, Czech Republic, June 7, 2013
- Update on PCOS, Natal, Brazil, August 20-21, 2013
- Update on PCOS, Quito, Ecuador, September 25, 2013
- 11th Annual Meeting of Androgen Excess & PCOS Society, Newport, Rhode Island, USA, October 17-18, 2013

ANNUAL MEETING OF AEPCOS SOCIETY

Newport, Rhode Island, USA,



11th Annual Meeting of AEPCOS Society will be held at the HYATT REGENCY RESORT HOTEL, 1 Goat Island, Newport, Rhode Island 02840, USA, October 17-18, 2013. The meeting will start October 17 at 4 PM to permit to people attending IFFS/ASRM meeting in Boston (that meeting is scheduled to finish October 17, at 1 PM) to can participate to AEPCOS meeting sessions. Newport is located 72 miles from Boston Convention Center (about 1 hour and 20 minutes by MA-24S). Transportation from Boston Convention Center to Newport Hyatt Regency Resort will be provided (bus leaving at 1:30 PM) but has to be reserved at least 15 days before.

The venue of 11th AEPCOS Annual meeting, Hyatt Regency Resort Hotel, is situated on Goat Island. Surrounded by Narragansett Bay, the hotel offers the seclusion of a private island, just minutes to downtown Newport. The resort provides water shuttle (and van shuttle) to/from downtown Newport.

Abstract deadline is August 2, 2013. For abstract form and preliminary program, please connect to: www.ae-society.org or contact: info@ae-society.org

Newport may be easily reached by car, by flight (25 miles from International T.F. Green/airport— PVD) or by train (18 miles from West Kingston railway station —along New York-Boston railway). A shuttle bus operates from both airport and train station to Newport hotels. For information or reservation on transportation, contact: info@ae-society.org

REGISTRATION FORM

11TH AEPCOS ANNUAL MEETING

REGISTRATION ONLY

_____AEPCCOS members \$260 _____Non AEPCCOS members \$360

NEWPORT HYATT REGENCY RESORT

\$219 for night ___October 16 ___October 17 ___October 18

Payment amount: \$_____ Credit card payment: ___VISA ___MasterCard ___AMEX

Credit card number_____ Expiration date:_____/_____

Cardholder
name_____

Online payment_____ To safely pay online, connect to: www.ae-society.org

Check payment_____ Make checks payable to Androgen Excess Society

Email, mail or fax the registration form to: Androgen Excess & PCOS Society, via delle Croci 47, 1st floor, suite 10, 90139 Palermo, Italy. Fax: +39-091328997, Email: info@ae-society.org

Only written cancellation by fax or e-mail will be accepted. For cancellations until September 1, 2013, a 50% fee will be applied. No refund will be given after that date. Registration includes welcome reception, lunch (Oct 17) 2 coffee breaks. Hotel prices include \$20 Resort Fee (parking, in room high-speed internet, water shuttle or van shuttle to/from Downtown Newport, resort activities, access to fitness center, 2 bottled waters for night) but do not include 13% combined city and state occupancy taxes.

The certificate will be issued to the name of the accredited participant.

To get registration form in word, please contact: info@ae-society.org

LETTERS FROM MEMBERS

We publish a letter from Michel Pugeat, M.D., related to the discussion about testosterone assay and the role of our Society in PATH (partnership for accurate hormone testing). Michel Pugeat is one of the founding members of AEPCOS Society and is Professor of Endocrinology at INSERM, Lyon, France.

Dear Enrico,

I fully agree with the what said Franck Stanczyk during his interview on problems in measuring testosterone in female and children.

I also share the position of AEPCOS Society in our participation as a partner in PATH. During the last meeting, that I missed in Reston, the strategy of PATH was apparently not well-defined. The tendency to claim that LC/MS is the gold standard looks a bit promotional for a few companies but not all, particularly for those still developing direct testosterone assay.

Our personal experience on mass spectrometry in measuring testosterone in women is quite in the line of the report by Legro et al, JCEM 2010. A good testosterone immunoassay with an extraction step before chromatography, gives us similar, but much less expansive results, in exploring properly hyperandrogenic patients.

It would not be easy for AEPCOS Society to play a leader role in PATH, but the politics of the empty chair would had been disastrous. So, I completely follow your recommendation to still participate in PATH with not so much current ambition... but anticipating the opportunity to validate testosterone assay in women.

All my best wishes

Michel

ABSTRACT SUBMISSION FOR 11TH AEPCOS ANNUAL MEETING

You are invited to submit abstracts of your original research to be considered for presentation at the 11th Annual Meeting of the Androgen Excess & Polycystic Ovary Syndrome Society.

To be considered for presentation your abstract must be submitted no later than August 2nd, 2013, 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 11th Annual Meeting of the AE-PCOS Society on submission of the abstract

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

All abstracts will be reviewed by a blinded scientific committee nominated by AE-PCOS Annual Meeting Committee.

**ANDROGEN
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Patricia Vuguin, M.D.

CHALLENGES IN DIAGNOSIS OF PCOS DURING ADOLESCENCE

Our associate editor, Tracy Bekx, has interviewed Patricia Vuguin, M.D., Associate Professor of Pediatrics at Cohen Children's Medical Center, North Shore LIJ Health System, Hofstra University, Long Island, New York, USA

1. Patricia, one of the biggest challenges in evaluating adolescents for PCOS is the overlapping features of PCOS with normal puberty. What are your thoughts in whether we should even consider the diagnosis of PCOS in this age group?

There is evidence to suggest that the presentation of PCOS in adolescence has its origins before or at the onset of puberty. We also know that some of the features that define PCOS in women may overlap with normal puberty. Anovulatory cycles often occur following menarche, and clinical evidence suggesting androgen excess (e.g., acne) is common during pubertal development. In addition, the normal adolescent ovary is also known to histologically resemble a polycystic ovary. Because of the overlapping features of PCOS with normal puberty, it has been recommended that the diagnosis of PCOS in adolescents be on hold until menstrual irregularity has persisted for two years. Labeling an adolescent with the diagnosis of PCOS may result in unnecessary treatments and impose further psychological distress, but delaying the diagnosis may have long term consequences. Androgen serum levels are preserved into adulthood and are reflected in fertility pattern during the third decade of life, the higher the androgen level the lower the fertility rate. Furthermore, adolescents and women with PCOS are at increased risk for impaired glucose tolerance and T2DM, obstructive sleep apnea, pregnancy complications, depression and anxiety, nonalcoholic fatty liver disease and nonalcoholic steatohepatitis, and possible endometrial cancer. Thus, by considering the diagnosis of PCOS during the adolescent years, we could potentially lessen or reverse the clinical and or biochemical abnormalities associated with the syndrome, pathologic changes that might be irreversible later on in life.

2. If considering PCOS in the adolescent, what diagnostic criteria would you recommend?

I would recommend the diagnosis of PCOS based on the presence of clinical and/or biochemical evidence of hyperandrogenism (after exclusion of other pathologies) and persistent oligomenorrhea including the presence of primary amenorrhea to frequent dysfunctional bleeding. I prefer to wait 2 years after the initiation of menarche but I would consider the diagnosis earlier if an older adolescent presents with primary amenorrhea or a younger hyperandrogenemic adolescent has significant menstrual irregularities. If the diagnosis is not clear I will emphasize the importance of follow-up.

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Ellen Connor, M.D.

3. What can we do as clinicians to improve our ability to accurately diagnosis this syndrome in this age group?

A high index of suspicion is needed to initiate an extensive evaluation of any adolescent girl with signs and symptoms of hyperandrogenism (hirsutism), or as soon as her menstrual irregularity becomes abnormal. One has to remember that the criteria to define menstrual cyclicity are different between adolescents and adults. Having less than 4 cycles during the first year post menarche, having less than 8 cycles between 2 and 5 gynecologic years, primary amenorrhea after the age of 15 years, no menstrual cycles 3 years after the appearance of breast, and menstrual bleeding that occurs more frequently than every 21 days or is excessive could all be consider abnormal. In, addition, we need to improve the way that we define biochemical hyperandrogenism with reliable assays that are validated for adolescents of different racial backgrounds. And lastly, we need to determine the role of the ovarian ultrasound as a possible criterion to diagnose PCOS.

The associate editor, Tracy Bekx has interviewed also Ellen Connor, M.D., Associate Professor of Pediatric Endocrinology and Diabetes and Co-Director of Adolescent PCOS Clinic, American Family Children's Hospital, University of Wisconsin, Madison, Wisconsin, USA

1. Ellen, knowing the heterogeneity of diagnosing PCOS in adolescents, could you summarize the findings from a survey performed among specialists, including gynecologists, pediatric endocrinologists and adolescent medicine physicians that has been published in the *Journal of Pediatric and Adolescent Gynecology*, 2012; 25:259-61

We found considerable heterogeneity among diagnostic workup approaches of the members of NASPAG, who are pediatric gynecologists, pediatric and reproductive endocrinologists, adolescent health specialists, and pediatric care providers. Once diagnosis was established, providers had more homogeneity among their therapeutic regimens, frequently recommending oral contraceptives and diet/lifestyle modifications.

2. What future studies are addressing this challenge?

Our group at NASPAG (Drs. Andrea Bonny, Ellen Connor, Cynthia Holland, Gina Sucato, and Veronica Gomez-Lobo) has designed a pilot study to assess the feasibility of a multicenter registry for adolescent PCOS patients by enrolling 100 adolescent patients identified as having PCOS.

A PCOS patient data registry has been developed to house de-identified anthropometric, historic, and laboratory data. The initial two years trial will involve Nationwide Children's, Children's National Hospital, Children's Hospital of Pittsburgh, and University of Wisconsin-Madison. Our intent is to subsequently enroll multiple centers to collect data that will allow us to clarify how adolescent PCOS is best diagnosed, and whether the different phenotypes of PCOS differ in androgen profiles, sonographic findings, or metabolic or other risks.