

AE-PCOS

ANDROGEN EXCESS & PCOS SOCIETY

NEWSLETTER

Strengthening care for women with Androgen Excess Disorders

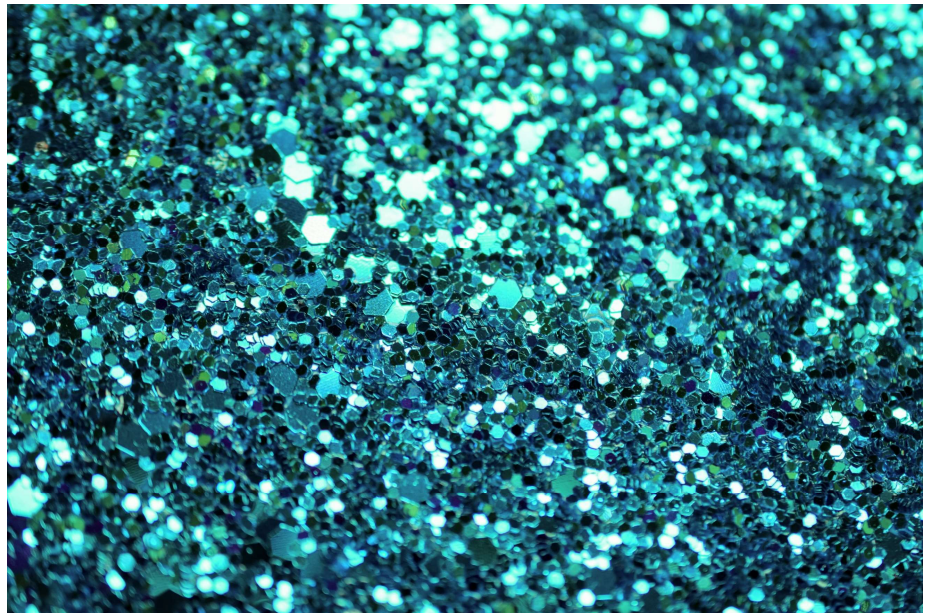


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FOREWORD

FROM THE PRESIDENT



Dear members of the AE PCOS society hope that all of you had a wonderful Christmas and a good start of 2024. It is going to be an exciting year I guess. It is the second year of my presidency and we will have some upcoming highlights this year as we had in the past year 2023. Looking back at the annual meeting in Rotterdam which was the best attended AE-PCOS meeting ever and we neither lost or earned any money. So I would like to express my gratitude to our CEO Anuja Dokras for taking care of all the financial and practical details coming along with these meetings.

Our newly appointed chief scientific officer (CSO) Elisabeth Stener Victorin has been communicating with the European counterpart of the Endocrine Society the ECE to organize the 2024 update meeting in conjunction with this society. In May 2024 we will have the first joined meeting with the European Endocrinology Society in Stockholm. It will be an interesting meeting with symposium embedded in the program of the ECE meeting and our update meeting just a day before the official program of the ECE starts. The theme of the upcoming update meeting is "Immune Function in PCOS" and Terhi Piltonen and Rebecca Campbell put together an interesting program with several renowned authorities in the field of immunology from all over the world. So if you can make it to Stockholm be our guest I would say!

We will also have a joined meeting with Indian PCOS Society in Mumbai in June of this year. Anuja Dokras and myself were invited speakers at this meeting which is generally very well attended by several hundred gynecologists and reproductive endocrinologists from all over India and surrounding countries. Duru Shah, the president of the Indian PCOS society, has put together an interesting and exciting program for that meeting.

Poli Mara Spritzer our Latin American board member reached the end of her term. I would like to thank Poli Mara for all the things she did as an active board member in the past years. I would also like to extend a warm welcome to our new board member Madhuri Patil who was elected by our members.

In the meantime, a lot of our members who were involved in the preparing the new International Guideline on PCOS are also co-authoring many meta-analyses and other papers that have been submitted to high impact journal during the last 9 months. Again, I would like to express my gratitude to them as well for doing this on top of their daily business. Thank you for being part in getting the important knowledge and messages from the guideline out into the world!

Near the end of the year we will have an annual meeting in a very special part of the world. The board of the AE PCOS Society decided to organize this meeting in Queenstown in New Zealand and hope to attract a lot of the southeast Asians scientific population to this meeting. The program of that meeting will follow soon and the theme that we have chosen for this meeting is "Long-term Health Sequelae of PCOS".

Cheers,

Joop Laven MD PhD REI
President, AE-PCOS Society

AE-PCOS

New society business

- The AE- PCOS would like to welcome our new board member:

Dr. Madhuri Patil MD, DGO, DFP, FCPS, FICOG (Mumbai)

- Reminders of next update meeting:

AE-PCOS Scientific Update Meeting:

Friday May 10 2024,

Stockholm, Sweden



- **Join up on Social Media:**

Our AEPCOS society has several social media accounts! Please follow us on

Twitter: [@aepcossociety](https://twitter.com/aepcossociety)

Instagram: [aepcossociety](https://www.instagram.com/aepcossociety)

Facebook: [Androgen Excess & Polycystic Ovary Syndrome](https://www.facebook.com/AndrogenExcessPolycysticOvarySyndrome)

Early Career Special Interest Group

BY JAMIE BENHAM

The Early Career Special Interest Group (EC-SIG) aims to support the professional development of early career professionals who have an interest in androgen excess disorders and polycystic ovary syndrome.

The EC-SIG objectives set by the Leadership Committee in collaboration with EC-SIG members are:

- 1) To expand collaborations between EC-SIG members.
- 2) To increase social media presence of EC-SIG to promote members and connect with early career professionals internationally.
- 3) To improve EC-SIG members knowledge about PCOS awareness initiatives.

The EC-SIG holds four meetings annually over Zoom. In addition, several Meet the Professor sessions are planned each year and in person events at AEPCOS meetings.

Join EC-SIG!

Please contact EC-SIG if you're interested in joining:
aepcos.ecsig@gmail.com

2023 Leadership Committee

Faculty Lead
Marla Lujan

Chairs
Snigdha Alur-Gupta
Nour El Houda Mimouni

Secretary
Sharmin Abbasi



**The next EC-SIG meeting is
April 17, 2024.**

EC-SIG CORNER

EC-SIG HIGHLIGHTS

- Meet the Profesor Session Dec 8 2023: **Prof. Melanie Cree**, MD, PhD, Pediatric Endocrinology University of Colorado Anschutz and Children's Hospital Colorado
- There are plans to start a 'Ted Talks' type series tentatively titled EDGE-PCOS = **Evidence-based Dissemination of Guidelines and Expertise** (in) PCOS that features ECSIG members.
 - Do you have ideas? Contact dr.basselwa@gmail.com
- **Let's connect and collaborate:** AEPCOS ECSIG Research Interests google page- connect with us to hear more at PCO ECSIG aepcos.ecsig@gmail.com

Upcoming:

1. EC Panel Discussion: **Progress and Pitfalls in Management of PCOS in Asia: 14th March, 2024 8AM NY EST, 5:30PM IST**



2. Next Quarterly EC – SIG Meeting : **17th April, 2024 8AM NY EST** (Zoom calendar link has been sent out!)
3. PCOS Challenge Advocacy Day: 18th April, 2024
4. AEPCOS Update Meeting: 10th May, 2024 in Stockholm Sweden. Please reach out to her if you are also going to be there!
5. The 13th Congress of the Asia Pacific Initiative on Reproduction (ASPIRE 2024) will be held at the Philippine International Convention Center (PICC), Manila, Philippines from 23 – 26 May 2024. Further information can be found here: <https://www.aspire2024.com/aspire/>

Research updates:

Everything you always wanted to ask about sex in PCOS but were afraid to ask.

Joop S.E. Laven

Polycystic ovary syndrome (PCOS) stands out as one of the most prevalent endocrine disorders among women of reproductive age, impacting approximately 6.5% to 15% of women¹. Being a syndrome, PCOS manifests with diverse clinical presentations, marked by significant features like irregular menstrual cycles, absence of ovulation, elevated androgen levels, infertility, and an elevated susceptibility to quality of life concerns such as depression, anxiety, and low self-esteem². More recently, studies have indicated a higher prevalence of sexual dysfunction in women diagnosed with PCOS³.

A meta-analysis indicates that women with Polycystic Ovary Syndrome (PCOS) experience impaired sexual function compared to control women, with effect sizes ranging from small to large. Sexual function assessments through questionnaires reveal slight impairments, particularly in areas such as arousal, lubrication, orgasm, and sexual satisfaction. Furthermore, according to Visual Analogue Scale (VAS) scores, women with PCOS report fewer sexual thoughts and fantasies, as well as a reduced likelihood of forming relationships compared to control women. Substantial impairments are noted in terms of sexual attractiveness, satisfaction with their sex life, and the impact of their physical appearance and body hair on sexuality. The effect sizes observed in these studies are generally clinically relevant, underscoring their significance for healthcare providers³. A recent study confirming the impact of PCOS on sexual function failed to establish a relationship between the experienced sexual distress and endocrine parameters such as androgen serum levels⁴. Similarly, although one would expect that hirsutism is associated with sexual dysfunction in women with PCOS this seems not to be the case⁵.

It is known that hyperandrogenism expressed as free testosterone had a U-shape effect in sexual dysfunction, because both in the case of deficit and in the case of excess, sexual function is impaired⁶. However, the degree of depression seemed to be directly linked to extent of the sexual dysfunction⁷. In a fairly large Chinese study the extent of the sexual dysfunction was most pronounced in the full blown phenotype having ovulatory dysfunction, hyperandrogenism and polycystic ovaries⁸. Weight, body image and anxiety related to sexual activities seem to be significant components in the development of sexual dysfunction in PCOS patients⁸. The latter study concluded that excess weight leads to an impairment in body image perception, to anxiety and avoidance behavior related to sexual activities. These aspects seem to be a significant component of sexual dysfunction in the case of PCOS patients, beyond the effect due to hormonal changes such as changes in androgen levels, LH and FSH values and BMI. This underscores the importance of addressing body image issues and anxiety related to sexual activities in the treatment of patients with PCOS^{8,9}. The frequency of sexual dysfunction in women with PCOS is a common finding. Body Mass Index (BMI) plays a noteworthy role in influencing sexual desire and arousal, with hirsutism demonstrating a significant impact in all areas under investigation, excluding dysphoria. Research indicates that women with lower levels of education and irregular menstrual cycles are more susceptible to sexual dysfunction. Similarly, individuals experiencing infertility and hair loss are also prone to encountering challenges in sexual function⁹.

Research update continued:

Everything you always wanted to ask about sex in PCOS but were afraid to ask.

Psychosexual function seems to be compromised in individuals with PCOS, yet there is a vast amount of evidence regarding associated distress scores, essential for meeting the criteria for psychosexual dysfunction. Healthcare providers should engage in conversations about both sexual function and distress, recognizing the multifaceted factors influencing sexual function in PCOS. Subsequent research endeavors should strive to evaluate both psychosexual function and distress, contributing to a more comprehensive understanding of the extent of psychosexual dysfunction in individuals with PCOS¹⁰.

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Highlighting Recent publications:

Belsti, Y. *et al.* (2024) 'Diagnostic accuracy of oral glucose tolerance tests, fasting plasma glucose and haemoglobin A1C for type 2 diabetes in women with polycystic ovary syndrome: A systematic review and meta-analysis', *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*, 18(3), p. 102970. doi:10.1016/j.dsx.2024.102970.

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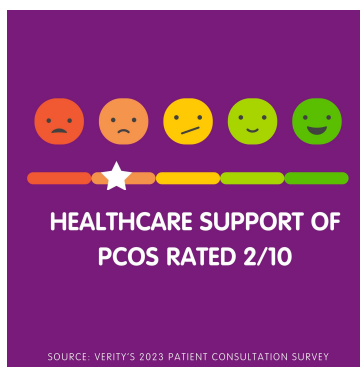
Consumer engagement Update

Verity (PCOS UK)

As ever, we are very busy with lots of different activities at Verity. Some highlights over the last few months include:

- Our PCOS Patient Consultation 2023 found that UK PCOS patients rate the care they receive for PCOS within the NHS a 2 out of 10
- Being invited to the illustrious Cambridge Union to take part in a panel on reproductive health
- One of our Trustees was accepted as an official UN Women's Delegate for this year's two week global UN conference from 06-17 March 2023
- Presenting on PCOS at a free event for refugees and asylum seekers on International Women's Day
- Ongoing duties on the board for the NHS Confederation; looking at inequalities in women's health
- Co-authored [paper](#) on healthcare and research priorities for those living with PCOS (Bassel H. Al Wattar, Jhia Jiat The, Sophie Clarke, Ali Abbara, Vikram Talaulikar)
- Co-hosted an amazing patient webinar alongside Daisy PCOS and Dr Weibke Arlt on the Daisy study and early findings from Dr Arlt's research. An amazing 85% of attendees said it increased their interest in taking part in research, and one patient said, "Such breakthrough research - most hopeful I've felt in my 40 year PCOS journey!"
- Launched a new feature on our blog where we are highlighting an early careers researcher each month. In January, we introduced our readers to [Dr Heidi Vanden Brink](#) from Texas A&M University and in February, [Dr Jillian Tay](#) from Monash Centre for Health Research
- One of our Trustees travelled from the UK to the US to take part in the COMET-CVD advisory board kick-off meeting led by Dr Anuja Dokras

To keep up to date with Verity, please follow us on X (formerly Twitter) @veritypcos



Pictured: Left- Emma from Endometriosis UK, Rachel from Verity, Dr Nightat Arif a NHS GP and TV Presenter and Professor Harbinder Sandhu from Warwick University at Cambridge University Union Panel

Right- Sasha from PCOS Challenge, Ashley from @PCOSGurl and Caroline from Verity at the COMET-CVD meeting

MEMBER ENGAGEMENT

We are pleased to share news from our members:

Polycystic Ovary Syndrome (PCOS) and Hirsutism Outpatient Clinic at Yeditepe University,
Istanbul, Türkiye www.yeditepe.edu.tr

The PCOS and Hirsutism Outpatient Clinic at Yeditepe University wanted to highlight their multi-disciplinary team. They are dedicated to caring for those with androgen excess disorders and are open to international studies.



Dr. John Barry, Clinical, Educational and Health Psychology, London

Dr. Barry is pleased to announce that his book on Psychological Aspects of PCOS was translated from English to German. Here are the links to his publications:

English <https://link.springer.com/book/10.1007/978-3-030-30290-0>

German <https://link.springer.com/book/10.1007/978-3-031-24461-2>

Dr. Rashida Begum, Founder of Infertility Care and Research Centre in Bangladesh

Congratulation to Dr Begum on receipt of a fellowship from Indian College of Reproductive Medicine.

Dr. Stephanie Mohammed, Trinidad and Tobago

Congratulation to Dr Mohammed on many successes including:

- Recipient of Principal's Award for most outstanding graduate researcher from the University of the West Indies
- Best Poster Award under the theme Regional Health Issues and Advances: Entitled: "The PCOS Epidemiology and Phenotype in Trinidad and Tobago (Trinidad-Pep) Study: Preliminary Result"
- Recipient of Paul Haris Fellow Award by Mr. Brian Glasgow, Rotary District 7030 on behalf of Rotary Clubs of Central Port of Spain, Felicity/Charlieville, Princes Town, San Fernando, and St. Augustine
- Will be Starting a postdoctoral position at the University of Pennsylvania to continue research on PCOS and in general women's health



CALL FOR NEWSLETTER CONTENT

Share with us any news or announcements.

We want to hear from you!

Interested members please email newsletter@ae-society.org.

Use the subject line "Member engagement"

CALENDER OF EVENTS

- South Asian Early Career Panel: Mar 14 2024 **Progress and Pitfalls in Management of PCOS in Asia: 14th March, 2024 8AM NY EST, 5:30PM IST via Zoom**
- **AE-PCOS Scientific Update Meeting: *Immune function in PCOS*** Friday May 10 2024, ECE Stockholm, Sweden
- The 13th Congress of the Asia Pacific Initiative on Reproduction (ASPIRE 2024) Manila, Philippines from 23 – 26 May 2024. <https://www.aspire2024.com/aspire/>
- September 2024 **62nd Annual Meeting of the European Society for Paediatric Endocrinology** Liverpool, UK

HOLD THE DATE!

November 7-9, 2024

22nd Annual Meeting of the Androgen Excess and PCOS Society

The meeting will be held in Queenstown, New Zealand at the Millenium Hotel from 7th to 9th November 2024. The theme for the 22nd Annual Meeting will be ***Life-Long Sequelae in PCOS***. The meeting will explore recent mechanistic and clinical advances related to cardiovascular, metabolic and psychological health in this chronic, lifelong condition, highlighting the latest research findings in PCOS-related basic and clinical research.

