



NEWSLETTER

Strengthening care for women with Androgen Excess Disorders



Photo by Jingda Chen from Unsplash

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20 - 22 October 2022, Anaheim, CA, USA

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FOREWORD

FROM THE PRESIDENT

AEPCOS Society at 20 years-leading the way forward

Let me start wishing you all a very happy and successful 2023! As your new president I would also very much like to welcome our new members who joined us in 2022. Moreover, a heartfelt thank you for all the other members for their support of our Society. We are looking back at a very good 2022 during which we could meet in person again after two years of COVID 19 misery making in person meetings impossible. The first meeting, at which we could meet each other again was in conjunction with the ENDO 2022 meeting in Atlanta, Georgia. This AE-PCOS annual meeting was dedicated to the role of the brain in PCOS and was a huge success. We had quite a few people attending this meeting in person whereas others decided to stay in the virtual space. Nonetheless the science at this meeting was of outstanding quality with similarly outstanding speakers. At the second meeting which was organized just prior to the annual meeting of the American Society of Reproductive Medicine (ASRM) in Anaheim California was also a big success. I had to leave early and couldn't attend that meeting but later learned that I had missed a very good meeting in terms of science but also in terms of friendship! I am very sorry that I couldn't address you there as your new president but I will catch up with you all on the next occasion in Chicago I guess.

Looking forward to what 2023 is going to bring us there is a very nice update meeting coming up just prior to the ENDO 2023 meeting. The program will be published soon on the website and the meeting is dedicated to body composition in PCOS. In 2023 it is also 20 years ago that the Rotterdam consensus meeting was organized by Bart Fauser and Basil Terlatzis in Rotterdam, The Netherlands.



Later on from October 5th until the 7th 2023 we will have the annual meeting in Rotterdam. At this meeting we will look back and forward in terms of PCOS diagnostic consensus criteria and will probably revise the Rotterdam criteria knowing that some criteria need revision due to new scientific insights in PCOS. The venue for that meeting will be exceptional since it is going to be held at a former Holland America cruise ship which has been refurbished into a classy hotel. The ship SS Rotterdam has a long history and we will have our meeting in the theatre in which celebrities such as Frank Sinatra, Aretha Franklin and many, many others have been performing. I look forward to welcome you all in Rotterdam at the SS Rotterdam!

Last but not least a lot of our members have been involved in updating the former 2018 International Guideline on PCOS. I would like to thank you all for doing so. A few others that were not involved in this process are going to be asked to critically review the current 2023 updated guideline in the very near future. Hopefully the guideline will appear somewhere in the late spring or in the early summer of this year. Another landmark in which our society was very much involved. So 2023 will be a very exciting year for our society as well as for all of you, the members of the AE-PCOS society.

Cheers,

Joop Laven MD PhD REI

President, AE-PCOS Society

AE-PCOS

20th ANNUAL MEETING

Oct 20-22, 2022 in Anaheim, California

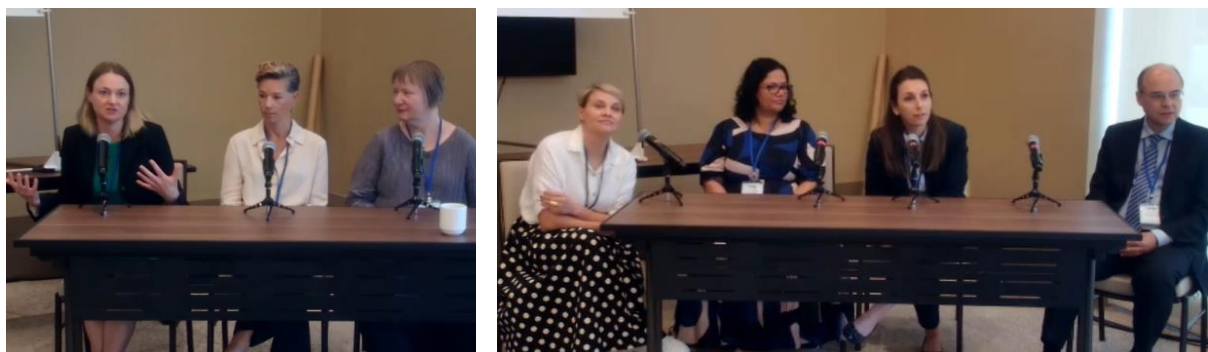
By Alyse Goldberg

- Dr. Campbell put together a rigorous syllabus to highlight research advances.
- The first evening event was a small group discussion outlining where PCOS research has been and where it needs to go. There was a unanimous call to unravel the underlying pathophysiology, and identify targets of future therapeutics.



Day 1: PCOS through the years:

- Day 1 began with the AEPCOS past presidents describing the inception of society and how it has evolved over the past 2 decades. There has been changes in focus of PCOS which has in the past been focused on ovaries, then androgens, then metabolic profiling. Recent advances in genetics and epigenetics are opening up future opportunities. Dr. Teede and her team are confronting in the midst of guideline updates with the help of the EC SIG team. Sifting through the plethora of less than rigorous studies has highlighted the need for keen critical appraisal of available data. There are exciting opportunities with the data sets from Finland and Australia, as well as novel approach with AI and machine learning. Future goals of altering susceptibility of this population will benefit understanding the effects of androgen and AMH exposure in utero for both male and female offspring who are both have specific phenotypes as a result.
- Dr. Alrt introduced us to an “ice cream cone” of 3 phenotypes of PCOS with steroid metabolone clustering that may suggest a novel approach to metabolic risk stratification.
- Dr. Cree- Green reviewed the roll of dysregulated glucagon in the PCOS seen in type 1 diabetes. She highlighted the challenge of predicting patients who will develop insulin resistance based on standard lab assessment and that elevated ALT should raise concern about future diabetes.
- There is great need for better testing of GLP1RA, Ppar a/y, SGLT2 and new GLP1-GIP in PCOS and T1DM.



Advocacy Groups:

- We were fortunate to have representatives from PCOS challenge, Verity and Korento to remind us of patient perspectives and to focus on patient concerns when we pursue research questions and clinical studies (and condition naming).

Congratulations to our award winners:

- Dr. Vanden Brink presented on her work capturing the roll of 3D ultrasound in predicting persistent menstrual irregularity. Dr. Lujan later also consolidated the roll of US and potential to outperform alternative diagnostic criteria.
- Dr. Yh Ng detailed her large population studies determining cardiometabolic risk in offspring of mothers with PCOS.
- Dr. Yildiz shared with us his award winning research remotely and led us through the progression of studies about PCOS and the gut microbiota.
- Finally, Dr. Padmanabhan took us through her years of experience with research with the sheep model and the wisdom she has gained in the process.
- We were fortunate to hear about the contributions of Dr. Louis DePaolo over his many years at the NICHD in both clinical and basic science.

**Day 2 sessions focused on PCOS natural history:**

- Drs. Joham, Piltonen and Tess Cherlin highlighted the change PCOS over the lifespan and all the systems that are affected by this disorder including mental health, sleep and long term CVD risk.
- Dr. Dos Reis discussed the roll of fertility intervention and shared clinical pearl to approach IVF including use of progesterone over OCP to start cycles. There was reassurance in the data that although patients with PCOS may need fertility optimization, most do successfully conceive.
- In the anticipated debate between Drs. Dokras and

Huddleston, there was consensus that we should not change the classification of PCOS to include more “alphabet soup” but assessment and reassessment of the metabolic status is crucial to optimization the health of our patients.

- The basic science oral presentations led to interest in LH hormone and receptor targets and novel alleles in the PCOS Gwas studies.

Outside of the lecture program, many collaborations and mentorships were established. The EC SIG group were guided through grant process and publishing by Drs. Stephen Franks and Louis DePaulo. The support within the society was very evident to all who participated.

We are much looking forward to future meetings in 2023.



EC-SIG CORNER

New EC-SIG Leadership Team!

Chair



Dr. Snigdha Alur-Gupta
MD

University of Rochester
New York, USA

Snigdha Alur-Gupta is a board-certified reproductive endocrinology and infertility specialist. After completing her medical degree at Sidney Kimmel Medical College, she did her Obstetrics and Gynecology residency at the University of Rochester before going to University of Pennsylvania for her fellowship. Being mentored by Dr. Kathleen Hoeger and Dr. Anuja Dokras cultivated her research interests in PCOS. She completed her fellowship thesis in PCOS was awarded the ASRM Prize Paper Award in 2019.

She is currently an Assistant Professor at the University of Rochester where part of her work is in a multi-disciplinary PCOS clinic. She was inducted into the ASRM/NICHD/DUKE Clinical Research/ Reproductive Scientist Training (CREST) Program in 2022 and is pursuing clinical research exploring the long-term health outcomes and mental health issues in PCOS. She is honored to be the next AEPCOS EC-SIG Co-Chair and hopes to use her term to expand mentorship between early career and mid-late career members and collaborate with PCOS patient advocacy groups.

Nour Mimouni is a postdoctoral fellow researcher at Columbia University, she performed her PhD and first postdoc working with Dr. Paolo Giacobini at the National Institute of Health and Medical Research (France) and University Hospital of Lille, where she worked on translational research projects which aimed at dissecting the central mechanisms underpinning the *in-utero* onset and transgenerational transmission of Polycystic Ovary Syndrome in adulthood, while exploring diagnostic and therapeutic tools to treat the condition. She was recently awarded the Rising Talent Prize – For Women in Science program – L'Oréal/ UNESCO and the award of Outstanding advances in Biology 2022 on PCOS research by the French National Academy of Science.

Nour is delighted to be the next AEPCOS EC-SIG co-chair and will work tirelessly to contribute to the EC-SIG growth over the next years.

Chair



Dr. Nour Mimouni
PhD

Columbia University

Secretary



Dr. Sharmin Abbasi
FCPS, MCPS, FACS (USA),
FMAS, FART, MBBS
 Anwer Khan Modern Medical
 College Hospital
 Bangladesh

Dr. Sharmin Abbasi is a fertility specialist and Associate Professor of Obstetrics and Gynecology in Anwer Khan Modern Medical College Hospital. Her research is focused on advancing basic and clinical knowledge about endometriosis, adenomyosis, infertility, ART, PCOS and recurrent pregnancy loss. She also has an interest in minimally invasive surgery and fertility preservation.

Sharmin has many leadership roles: founder joint secretary of PCOS club of Bangladesh; coordinator of many PCOS Awareness Program; International Editor of International Journal of Human Reproduction Research and Development (IJHRRD); reviewer of multiple journals; and advisor of the scientific committee of FIGO World Congress 2023 in Paris. She has been the recipient of many awards for her research and presentations in addition to pursuing research in PCOS, she regularly writes in newspaper and done advocacy programs for women with PCOS and endometriosis in the media. She regularly gives talks in national and international conferences on PCOS to disseminate the updated knowledge.

Sharmin wants to devote her academic and clinical works for the highest services of women's health.

EC-SIG PUBLICATIONS

- Lau GM, Elghobashy M, Thanki M, Ibegbulam S, Latthe P, Gillett CDT, O'Reilly MW, Arlt W, Lindenmeyer A, **Kempegowda P**; PCOS SEva Working Group. **A systematic review of lived experiences of people with polycystic ovary syndrome highlights the need for holistic care and co-creation of educational resources.** Front Endocrinol (Lausanne). 2022 Dec 2;13:1064937. doi: 10.3389/fendo.2022.1064937. PMID: 36531482; PMCID: PMC9755159. [\[Link\]](#)
- Elhariry M, Malhotra K, Solomon M, Goyal K, **Kempegowda P**. **Top 100 #PCOS influencers: Understanding who, why and how online content for PCOS is influenced.** Front Endocrinol (Lausanne). 2022 Dec 7;13:1084047. doi: 10.3389/fendo.2022.1084047. PMID: 36568090; PMCID: PMC9768020. [\[Link\]](#)
- Persson, S.; Ubhayasekera, K.A.; Bergquist, J.; Turkmen, S.; Poromaa, I.S.; **Elenis, E.** **Hyperandrogenic Symptoms Are a Persistent Suffering in Midlife Women with PCOS; a Prospective Cohort Study in Sweden.** *Biomedicine* **2023**, *11*, 96. <https://doi.org/10.3390/biomedicine11010096> [\[Link\]](#)

Early Career Special Interest Group

Join our group!!!!

BY JILLIAN TAY

Our mission is to support the professional development of early career professionals interested in androgen excess disorders and polycystic ovary syndrome (PCOS). This is accomplished by:

- Providing a forum for networking and collaborating with peers and AE-PCOS Society members,
- Establishing a platform to enable communication among AE-PCOS Society members and the broader research community,
- Providing a resource for topics of interest to EC-SIG members relating to career development, leadership and networking.

The initiatives set forth by the EC-SIG are determined by the EC-SIG members and the Leadership Committee. We hold 4 quarterly meetings, as well as organizing 3 Meet-the-Professor events with our members every year.

Inquiries about joining the EC-SIG

Please contact us at

aepcos.ecsig@gmail.com

2022 Leadership Committee

Faculty Lead

Marla Lujan

Chairs

Snigdha Alur-Gupta

Nour El Houda Mimouni

Secretary

Sharmin Abbasi



PCOS and Cancer: A story about associations and confounders

BY JOOP S.E. Laven, M.D., Ph.D., REI and FRDCOG.

Introduction

A recent publication in JAMA Oncology indicated a relationship between PCOS and pancreatic cancer. Whenever such a paper pops up it causes a lot of distress amongst our patients and care providers taking care of women with PCOS. Apart from some major flaws in the design of this study, such as self-reported PCOM instead of PCOS, it was merely an association and probably not a causal relationship ¹.

There is a group of genital cancers which have been related to endocrine factors and menstrual dysfunction e.g. endometrial, breast and some types of ovarian cancer. Apart from PCOS several other factors may also contribute to this specific oncological risk, including lifestyle, sexual as well as reproductive aspects, endocrine treatments, metabolic and diet components, excessive body weight, sedentary lifestyles, toxic habits, and aging. Therefore, cancer risk in women with the PCOS are in some way a puzzle in which the syndrome severity and specific treatments and lifestyle factors might influence the risk of developing some gynecological cancers ².

Breast Cancer:

Several systematic reviews that have evaluated available literature for the risk of breast cancer in women with PCOS could not find a consistent association between PCOS and breast cancer risk (see for review)¹. In 2015, a large Danish cohort study determined that breast cancer risk in PCOS patients was similar to that found in the general population³. Data of a recent Swedish register including a cohort of all females aged 15–50 years between 1985 and 2009 indicated no association between PCOS and breast cancer⁴. An important confounder might be the use of the oral contraceptive pill. Current use might increase the risk for breast cancer slightly. The available data did not find relationships between PCOS and breast cancer risk.

However, well-projected studies in this field are needed to obtain more robust conclusions. Particularly, studies evaluating breast cancer risk among OC PCOS users are required.

Ovarian Cancer

Although there is some recent genetic data pointing in the direction that DNA hypomethylation and sharing of common miRNA and mRNA features as those observed in ovarian cancer are also seen in women with PCOS suggesting a higher ovarian cancer risk in this population^{5,6}.

Two studies have not found an increased risk of ovarian cancer in PCOS women^{7,8}. Another cohort study reported that patients with PCOS who reported absent or irregular menstrual periods did not have an increased risk of ovarian cancer⁹. In contrast however, data from the Swedish cohort reported indicate that the risk of ovarian cancer is increased in women with PCOS⁴. Larger cohort studies with detailed information perhaps may provide clearer answers about the risk of ovarian cancer in women with PCOS. Finally, the number of clinical studies concerning the link between PCOS and ovarian cancer are limited. Additionally, the number of patients evaluated in some studies are very low. Another problem is related to overlapping risk factors, such as obesity, diet, smoking, and alcohol drinking¹.

Endometrial Cancer

The first report about the association of endometrial cancer and PCOS was from Speert in 1949¹⁰. Endometrial changes among PCOS patients are profound and might give rise to implantation failure and proliferative aberrations. The background of these derangements is mainly due to anovulation and prolonged unopposed estrogen exposure in the absence of sufficient progesterone exposure of the endometrium¹¹.

In addition to these factors hyperandrogenism as well as LH over secretion constitute risk factors for endometrial cancer since they promote growth of endometrial cells^{12,13}.

Numerous studies indicate an increase of endometrial cancer in PCOS women. Recently, endometrial neoplasia was evaluated in a large cohort of Thai women with PCOS. Women with a thick endometrium had an 8.7% risk of endometrial neoplasia¹⁴. In addition, the Swedish cohort study reported an increased risk of endometrial cancer in women with PCOS⁴. Metabolic syndrome as well as insulin resistance and diabetes mellitus have also been identified as risk factors for endometrial cancer. Interestingly, the co-treatment of endometrial cancer patients with metformin has been associated with a reduction of overall mortality¹⁵. Hence, it seems that by maintaining an appropriate metabolic and endocrine control of PCOS patients, during their entire life, may in fact reduce their risk of developing endometrial cancer¹.

Conclusion

Links between PCOS and gynecological cancer risk should also be taken into account, despite the fact that these links are controversial and related studies limited. It seems that the risk for endometrial cancer is increased in women with PCOS. The risk for other gynecological malignancies such as breast cancer and ovarian cancer seems not to be increased. In general, more well designed and projected clinical studies should be performed to better understand the association between PCOS and gynecological cancer risk. And of course we are talking about associations and the causal link to be established as well, because there are also numerous confounders and other risk factors active that might explain the association!

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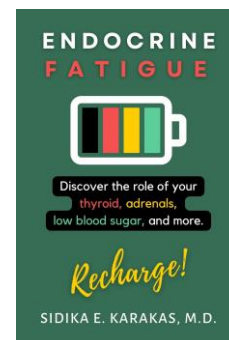
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MEMBER ENGAGEMENT

We are pleased to share news from our members:

Sidika E Karakas MD, Davis CA, USA

Dr. Karakas published the E-book: "Endocrine Fatigue: Discover the role of your thyroid, adrenals, low blood sugar and more...". Fatigue, a common complaint in PCOS, is a challenging referral diagnosis for endocrinologists. Differential diagnosis is complex; work-up can be extensive and time consuming. Patients usually need additional information and support. She wrote this patient-friendly book with the goal to help colleagues, trainees, and patients.



Kendall Soucie PHD, Windsor, Ont Canada

Congratulations to Dr. Soucie and team who was recently awarded an award to study PCOS by: [Award Recipients for Insight Development Grant: February 2022 Competition \(sshrc-crsh.gc.ca\)](#)

Kendall Soucie (PI/PA), Patti Fritz, Jessica Kichler, Heather Lawford, Jen Rinaldi (CO-Is), Nicole Markotic, and Stacey Williams (Collaborators) *Building an inclusive, resiliency- based framework to support women with polycystic ovary syndrome across the lifespan.* (\$64,808) SSHRC Insight Development Grant. (2022-2024).

Their project was featured in a local community magazine! (The Drive)--they did a spread on our research at the University of Windsor on PCOS. [Current Issue | The Drive Magazine](#)

More information available at: <https://www.healuwindsor.com/>

Letisha Bates, USA



As a PCOS health coach, nutritionist, and advocate, Letisha Bates had the honor of receiving the PCOS Challenge Ricardo Azziz Advocacy Leadership Award in September of 2022.

As a PCOS Regional Leader Advocate on a legislative levels, she has helped raise over \$15,000 towards PCOS research and education.

Find her at thatpcoscoach.com, or [@thatpcoscoach](#)

Punith Kempegowda MD, Birmingham, UK

Dr. Kempegowda's team has created patient education tools available on YouTube focusing on PCOS and fertility, PCOS and skin health and PCOS and emotional wellbeing:

https://www.youtube.com/playlist?list=PLQGMo8zM9RkX_bVOK3QkzhRgag1bFs5jX
[@drpunith](#) or <https://sites.google.com/view/punith>



CONSUMER ENGAGEMENT



WILLIAM R. PATTERSON

Director of Public Affairs

William is the CEO of The Baron Solution Group, a Top 100 MBE. He was named a Top 20 Business Icon by Exceptional People Magazine. William is a four-time award-winning lecturer and international best-selling author who uses his trademark approach, The Baron Solution™, to coach, train and motivate nonprofit leaders, small business owners, executives, sales professionals and investors.

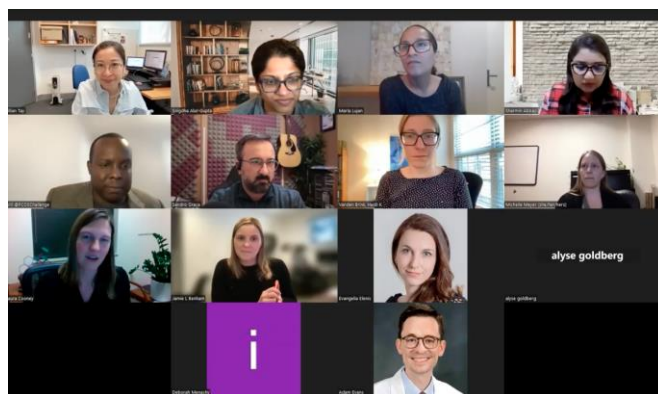
As Director of Public Affairs of PCOS Challenge, William had joined us at the AEPPOS EC-SIG Meet the Professor Session in December 2022!



About PCOS Challenge

Serving over 55,000 members, PCOS Challenge: The National Polycystic Ovary Syndrome Association is the leading 501(c)(3) nonprofit patient support and advocacy organization globally that is advancing the cause for women and girls with PCOS.

Our Mission: Raise public awareness about PCOS and help people with the condition overcome their symptoms and reduce their risk for life-threatening related diseases such as diabetes, cardiovascular disease and cancer.



Engaging with our EC-SIGs!

The EC-SIG Meet the Professor Session was held in December 2022 on Zoom meeting, thanks to the efforts of our EC-SIC leadership team. The meeting was well attended by our members globally with enthusiastic discussion at the end for potential collaboration on supporting PCOS research, outreach and patient care.

William has shared with us how PCOS Challenge has started and continued to grow with increasing impact on advocacy. The 2022 PCOS Awareness Month to date had up to 90 million media impressions, more than 700k people engaged, and nearly 200 Landmarks Illuminate Teal for PCOS around the world.

2022 PCOS AWARENESS MONTH HIGHLIGHTS AND IMPACT

UP TO
90 MILLION
MEDIA IMPRESSIONS

NEARLY
700,000
PEOPLE ENGAGED

OVER
550
PARTNERS

3 NATIONAL CAMPAIGNS
WITH OVER
2,000
PARTICIPANTS

HELD THE LARGEST PCOS
EDUCATIONAL EVENT WITH
1,000
PATIENTS & PROVIDERS

OVER
200
TEAL LANDMARKS



Supporting PCOS Research

William introduced how PCOS Challenge can help support PCOS research. PCOS Challenge has a huge **PCOS Challenge Registry** with women predominantly from the US, but also internationally. The registry is governed by a **Patient Scientific Research Committee**.

Current active collaborating research projects include:

- PCOS Pregnancy and Maternal Health Study (PI: Anuja Dokras, Anne Kim, Iris Lee)
- PCOS Economic Burden Study (PI: Sasha Ottey, Ricardo Azziz)

Other **research-related services available** at the PCOS Challenge include:

- **Study design:** assist with study design, provide input on clinical endpoints and patient-reported outcomes, help with patient preferences and benefit risk assessments.
- **Study recruitment:** over 55000 members and the ability to geo-target recruitment efforts in any city or state in US. Help review or development of recruitment materials.
- **Site selection:** has in-depth knowledge of patient populations and relationships with many of the PCOS research centers in the US. Can help select optimal trial sites to maximize recruitment.
- **Focus groups:** create focus groups to help provide information on unmet patient needs and unlock new insights to help inform discovery and development.
- **Patient-focused drug development:** work with industry to engage patients to give perspectives on their current approaches to treatment, incorporate patient input into FDA hearings and advisory committee meetings.
- **Clinical trial optimization:** advise on eligibility criteria for clinical trials; provide input to improve patient safety, comfort etc.; gather feedback from patient and scientific community.

THE PCOS CHALLENGE STUDY

For the Collection of Information to Advance Research and Improve Care for PCOS Patients

CO-PRINCIPAL INVESTIGATORS



Sasha Ottey, MHA, MT (ASCP)
Founder and Executive Director
PCOS Challenge:
The National Polycystic Ovary Syndrome Association



Ricardo Azziz, MD, MPH, MBA
Professor
The University of Alabama at Birmingham

Supporting ECRs

In the near future, PCOS Challenge hopes to set up an Early Career Researcher (ECR) Forum, with the aim to help ECRs build network with senior investigators for mentorship and future collaboration, as well as build connection with women with PCOS.

PCOS CHALLENGE 6 MAJOR PROGRAM AREAS

AWARENESS
SUPPORT & EMPOWERMENT
EDUCATION
ADVOCACY & HEALTH POLICY
ACCESS TO CARE
RESEARCH



AWARENESS



SUPPORT & EMPOWERMENT



EDUCATION



ADVOCACY & HEALTH POLICY



ACCESS TO CARE



RESEARCH

Visit <https://pcoschallenge.org/>

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For further information please email:
info@pcoschallenge.org

CALENDER OF EVENTS

ECE 2023: 13-16 May 2023, Istanbul, Turkey

AE-PCOS Scientific Update Meeting: 14th June 2023, Chicago, USA

ENDO Society: 15-18 June 2023 Chicago, Illinois

ESHRE Annual Meeting: 25-28 June 2023, Copenhagen, Denmark

AEPCOS Annual Meeting: Oct 5-7, 2023 Rotterdam, Netherlands

ASRM 14-18 October 2023, New Orleans, USA

Controversies in Gynaecology, Obstetrics and Infertility: 23-25 November 2023, Vienna, Austria

CALL FOR NEWSLETTER CONTENT

We want to engage with our society members!

Have you recently been awarded a prize/grant?

Have you been offered a new faculty position or made a career change?

Have you been invited to speak in a major event?

Are you a rising academic researcher looking for young potential PhD students?

Do you have a job/fellowship to offer?

Have you participated in any research translation work?

Maybe you started writing a blog or joined a twitter/Instagram account you would like us to follow?

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".

We suggest the content to be around 200-300 words with 1-3 accompanying images.

We are looking forward to seeing you in person at the next meetings:

AE-PCOS Scientific Update

Meeting: June 14, 2023, Chicago, IL, USA

ENDO2023
JUNE 15-18, 2023 CHICAGO, IL



Body composition in PCOS as part of ENDO 2023

REGISTER: [at Endo Society](#)

Save the date for the annual AE PCOS meeting entitled:

Twenty years after the 2003 Rotterdam PCOS consensus



**October 5, 6 and 7, 2023 on the SS Rotterdam,
Rotterdam, The Netherlands**