AE-PCOS
ANDROGEN EXCESS & PCOS SOCIETY

NEWSLETTER

STRENGTHENING CARE FOR WOMEN WITH ANDROGEN EXCESS DISORDERS

PRAGUE, CZECH REPUBLIC
9th May 2026

UPDATE MEETING

Novel Therapies For The Treatment Of PCOS

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Outline

PRESIDENT'S FOREWORD

Dear Society members,

What a moment! The misnomer of PCOS has long been recognized, and many PCOS experts have, over the years, raised the need to change the name. But it was not until now, when the field is saturated with information about the syndrome's vast health impact, that we were ready for the actual change. The rigorous process, steered by our society, Monash University, and the patient organization VERITY, made the change happen. Several patient organizations were involved, and they led the project. All our members were also able to vote on the new name options. The final decision was made by 90 people representing 56 different societies and organizations. Over several workshops, we narrowed down the options and finally settled on the current name. PCOS is now Polyendocrine Metabolic Ovarian Syndrome — PMOS!

With this decision, we hope to bring in new health professionals and harness their interests and expertise to advance healthy living with PMOS. Researchers are expected to gain more grant options once the nature of the syndrome is clarified by the name change. Most importantly, women and their concerns will be better heard, and their care will be more holistic rather than siloed and reproduction-focused.

But the work has just begun. A rigorous implementation strategy is ahead, and it will require all of us to make this decision a reality. We have linked some materials on our web pages that are helpful for dissemination work. You can download free materials to ensure the message is coherent and clear. Translations are available in many languages, and you can also help with new translations. If you want to be active, please get in touch with Professor Helena Teede for more information: helena.teede@monash.edu.

The Update Meeting in Prague was wonderful, and I thank all of you for your participation and lively discussion. Special thanks to Rebecca Campbell, Melanie Cree, and Anna Bennrick for pulling together the wonderful program, and to Tina Gorzek and Jamie Benham for the EC-SIG activities. Thank you, Lisa and Jim, for the support! Sandro Graca — great work on the name change and

social media activities! I think our society is now better mapped. I received strong feedback from attendees, and many new people expressed interest in engaging with our society and becoming part of it.

Now we head to Levi, Kittilä, Finland, for our Annual Meeting, where we will officially rename our society as the AE-PMOS Society! We will also renew our web pages and the logo, and we are happy to hear your suggestions. Heidi Vanden Brick and Tania Burgert are in charge of the website renewal.

Looking forward to seeing many of you in wintery Lapland. Together with Aled Rees and Maria Forslund, we have built a wonderful program. More information about the practicalities — where to fly, what to wear, and where to stay — can be found on our web pages.

Terhi Piltonen

President of the AE-PCOS Society

HIGHLIGHTS FROM THE UPDATE MEETING

AE-PCOS Update Meeting – Novel Therapies for the Treatment of PMOS

By: Tina Gorsek (Co-Chair of the EC-SIG) and Camille Gauthier

The AE-PCOS Society held its annual Update Meeting in Prague on the 9th of May 2026, co-located with the European Congress of Endocrinology (ECE). A full-day programme brought together leading researchers and clinicians from across the globe to present the latest advances in PCOS research, diagnostics, and treatment.

The meeting was opened with a warm welcome by Prof. Melanie Cree (University of Colorado), Prof. Anna Benrick (University of Göteborg) and Prof. Elisabet Stener-Victorin (Karolinska Institutet). Followed by a society news delivered by the Prof. Terhi Piltonen (The President of the AE-PCOS, University of Oulu) and Early Career – Special Interest Group (EC-SIG) updates presented by Tina Gorsek (Karolinska Institutet), highlighting activities and opportunities for early- and mid-career members.

The first session, Targeting Key Pathways in PCOS Pathophysiology, was chaired by Prof. Mojca Jensterle and Anja Dekanski and opened with a fascinating talk from Nathalie di Clemente (Inserm/Sorbonne Université), who presented data on blocking anti-Mullerian hormone (AMH) as a therapeutic strategy. Using a spontaneous rat model of PCOS, she demonstrated that an anti-AMH antibody restored ovulation and normalised androgen levels, providing compelling evidence that AMH plays a direct role in the ovulatory defect central to PCOS. Tanja Turunen (Karolinska Institutet) presented single-cell resolved findings on cell-type-specific endometrial dysfunction across the menstrual cycle in PCOS, shedding a light on the uterine environment and its potential contribution to a reproductive outcome. Helena Teede (Monash University) delivered a thought-provoking talk challenging the utility of cluster analysis for defining clinically meaningful PCOS subtypes. Her key message: the field should move toward dynamic risk prediction models to guide personalised treatment. The session concluded

with Damian Romero (Mississippi Medical Center) presenting a compelling case for targeting the androgen receptor (AR) to address cardiometabolic complications in PCOS. He offered an insight on PROTAC-based AR degrader, that avoids the hepatotoxic side effects of the usual AR inhibitors, offering a novel mechanistic approach beyond conventional anti-androgen therapy.

Session 2: Incretin Therapies, Mitochondrial Signals, and Cardiovascular Risk, chaired by Prof. Damian Romero and Lulia-Alexandra Pirga, opened with a comprehensive overview of GLP-1 and dual GLP-1/GIP receptor agonists in PCOS from Prof. Mojca Jensterle (University of Ljubljana). She highlighted multiple benefits beyond weight loss, including improved fertility, restoration of menstrual cyclicity, and increased rated of natural conception. Irem SonmezoglyKutuk (Hacettepe University) presented intriguing data on MOTS-c, a mitochondria-derived peptide, showing reduced circulating and skeletal muscle levels in women with PCOS. Dorte Glintborg (University of Southern Denmark) presented data from national Nordic cohort of 127,517 women with PCOS, demonstrating increased prospective cardiovascular disease risk compared to women without PCOS.

The session concluded with a series of rapid-fire talks covering a diverse set of topics: a lifestyle intervention RCT subgroup analysis showing particular benefit in women with overweight or obesity and PCOS (Christophe Richer dit Laflèche, Université de Sherbrooke); pro-inflammatory cytokine profiling across PCOS phenotypes (Martina Curcio, University of Udine); waist-to-height ratio as an assessment tool in a large European cohort (Tamara Baltic); 12-month outcomes from the ULTRA trial of ultrasound-guided ovarian ablation for PCOS-related infertility (Marwa Fakhreldin, Nuffield Health Derby Hospital); and a novel PCOS cell therapy approach using human GnRH cell repopulation in a GnRH-Killswitch mouse model (Jacob Short, Karolinska Institutet).

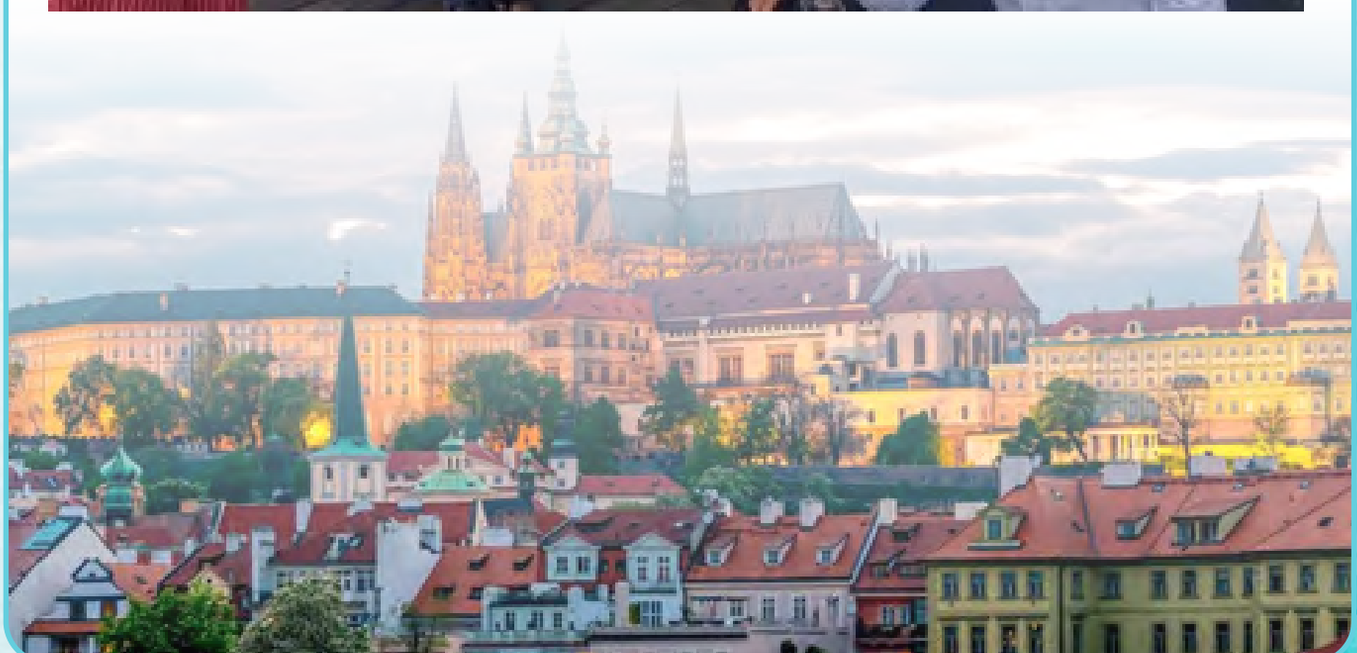
After lunch, Nathalie Di-Clemente and Sandro Graca chaired Session 3:PPAR Agonists, Hyperandrogenism and Androgen Signalling. Farheen Shaikh (Zydus Therapeutics Inc.) presented data on saroglitazar, a PPAR gamma agonist, as a treatment option in PCOS, with potential benefits across metabolic and reproductive outcomes. Andrea Rodriguez-Martin explored the role of hyperandrogenism in the development of metabolic dysfunction-associated steatotic liver disease (MASLD) in PCOS, adding to the growing body of work on the hepatic consequences of androgen excess. The session closed with the Caitlin MacRae (University of Otago) presenting her work on manipulation of peripheral androgen signalling to treat PCOS-associated metabolic dysfunction, using siRNA.

The session concluded with a second round of rapid-fire talks spanning an immunodeficient prenatal mouse model for therapeutic evaluation (Camille Gauthier, KI), mechanistic insights into intranasal insulin and postprandial energy expenditure (Colin Duncan, University of Edinburgh), SHBG and 11-oxygenated androgen associations (Eka Melson, MRC LMS London), menstrual cycle steroid hormone profiling by mass spectrometry (Meri-Maija Ollila, University of Oulu), genetic variation in gonadotropin signalling (Giangela Stokes, Northwest University), and the BRIDGE initiative for patient empowerment (Sumaya Osman, University of Birmingham).

Tanja Turunen and Prof. Melanie Creeopened Session 4: Cannabinoids, Enzyme Inhibition, and In Vitro Modelswith a presentation by Prof. Manuel Tena-Sempere (University of Cordoba) on combining cannabinoid and incretin pathways in PCOS treatment. Using the prenatally androgenised and pre-weaning DHT mouse model, his group systematically compared several compound combinations for their

effects on metabolic health. Lina Shiffer (MRC Laboratory of Medical Sciences) presented data on inhibition of AKR1C3, and androgen-activating enzyme, demonstrating selective decreases in systematic and intra-adipose 11-oxygenated androgens in women. Anja Dekanski (Karolinska Institutet) presented an in vitro endometrium model derived from insulin-resistant women with PCOS, offering a valuable platform for studying endometrial dysfunction and testing therapeutic interventions.

President Terhi Piltonen closed the meeting with a summary of the day's highlights and an enthusiastic promotion of the upcoming Annual Meeting in Levi, Finland and Update Meeting 2027 in Toronto, Canada.



THE NAME CHANGE EXERCISE

From PCOS to PMOS: *A New Name for a Complex Condition*

Mahnaz Bahri Khomami, on behalf of the Global Name Change Initiative

After decades of advocacy and several stalled attempts, polycystic ovary syndrome (PCOS) has a new name: Polyendocrine Metabolic Ovarian Syndrome (PMOS). Published in The Lancet in May 2026, this historic change is the result of one of the most rigorous and inclusive medical renaming processesreported to date, led by Prof. Helena Teede,alongside patient co-leadership and a global steering committee.

Why did the name need to change?

The term "polycystic ovary syndrome" has long been recognised as inaccurate and potentially harmful. It implies the presence of pathological ovarian cysts, which are not actually a feature of the condition, while obscuring the diverse endocrine, metabolic, reproductive, psychological, and dermatological features that define it. This misleading framing has contributed to delayed diagnosis, fragmented care, and significant knowledge gaps among clinicians. Research has shown that many women see three or more health professionals and wait over a year before receiving a diagnosis, with very few satisfied with their diagnosis experience or the information they received. The term has also contributed to stigma and unnecessary distress, with many women believing they have pathological cysts on their ovaries, causing fear and anxiety at the time of diagnosis and beyond.

How was the new name determined?

Previous efforts to rename the condition date back to 1995, with a 2012 NIH workshop formally recommending a change, yet without adequate patient engagement or governance, progress stalled. Crucially, before proceeding, a mandate for change was first established through global surveys of around 8,000 women with PCOS and health professionals, confirming widespread support for renaming the condition.This initiative built on that history differently. Funded by the Australian National Health and Medical Research Council (NHMRC) and led by the Centre for Research Excellence in Women's Health in Reproductive Life, administered by Monash University, the initiative brought together Verity [the UK's leading PMOS (formerly PCOS) patient charity], the Androgen Excess and Polycystic Ovary Syndrome (AE-PCOS) Society, and a global governance structure that engaged 56 academic, clinical, and patient organisations across all world regions. Using iterative Delphi surveys and nominal group technique workshops, the process gathered responses from 14,360 womenwith PCOS and multidisciplinary health professionals. Agreed guiding principles prioritised scientific accuracy, stigma avoidance, cultural appropriateness, and implementation feasibility.

The preferred terms (polyendocrine, metabolic, and ovarian) reflect the condition's multisystem pathophysiology. PMOS accurately captures the interacting endocrine abnormalities, the metabolic features present in the majority of those affected, and the ovarian dysfunction central to diagnosis, while eliminating the misleading reference to cysts.

What is happening next?

Implementation is already underway via an 8-stage global strategy: development of multilingual patient and clinician resources, integration into electronic health records, engagement with research funders and journal editors, and formal engagement with the World Health Organization (WHO) for adoption in the International Classification of Diseases. The new name will be incorporated into the 2028 update of the PCOS International Guidelines, which are used in 195 countries. Amanaged three-year transition period will support implementation.

This is more than a name change. It is an opportunity to reframe a complex multisystem condition, broaden research investment, improve diagnostic pathways, reduce stigma, and ultimately improve outcomes for the more than 170 million women affected worldwide.

RESEARCH UPDATE

by Em Prof. Joop S.E. Laven

Compromised research in PMOS: How big is the problem?

Clinical guidelines rely on sound evidence to underpin recommendations for patient care. Compromised research integrity can erode public trust and the credibility of the scientific enterprise, with potential harm to patients. Despite increased recognition of integrity concerns in scientific literature, there are currently no processes or guidance for incorporating integrity assessments into evidence-based guideline development or evidence synthesis more broadly. A recently developed tool, the RIGID Framework, uses a six-step approach to determinethe research validity of papers dealing with infertility treatment in patients with PMOS. Of the 101papers originally selected from PubMed, only 45 could be included in the guideline according to the RIGID Framework1.

In order to assess how many papers within the field of PMOS have been retracted over the years, I thought it would be a good idea to use this as the subject for my last contribution to this issue of the AE-PCOS newsletter. From 1999 to the present day, only 99 papers have been retracted dealing withissues associated with PMOS. This number is quite low because in the same time span, about 19,722 papers were published in which the MeSH term PCOS was used.

In 2026, 2papers were retracted, whereas in 2025, 2024, 2023,2022 and 2021, respectively, 2, 8,11,19 and 8 papers were retracted. The preceding five years spanning 2020 to 2015, respectively, 7,6,8,3,1 and 1 paper(s) were noted in PubMed as being retracted. From 2014 to 2010, 13 retractions were reported. In the first decade of this century, another 10 papers were retracted.

In total, 37 papers were from Egyptian authors whereas the second largest group came from China with about 35 papers retracted. Third in line was Italy with 7 papers, followed by Iran and Turkey with 3 retracted papers each. Pakistan and India had 2 retracted papers each, and Syria, Nigeria, Brazil, Portugal and the USA each had 1 paper retracted in the same time span.

The majority of retracted papers, e.g. 26, dealt with ovulation induction outcomes, most often using additional supplements on top of either clomiphene citrate or letrozole. Another 14 dealt with the positive effect of food supplements on the phenotype mostly looking at the effect of inositols. Fourteen papers were addressing the effect of laparoscopic drilling either alone or in combination with supplements on several ovulation induction outcome parameters. Twenty-one papers were addressing issues concerning the pathophysiology of PMOS and the majority of those dealt with metabolic issues such as insulin resistance and type II diabetes. Three papers addressed these issues in relation to pregnancy outcomes. Another 11 papers dealt with genetic markers and PMOS risk and phenotypical features. Most of these papers were also looking at regulatory RNAs. Four studies studied epidemiological factors such as the risk for type II diabetes and cardiovascular disease. Lastly, 2 papers studied ultrasound parameters in relation to treatment for infertility. A complete list of the retracted papers identified in this overview is provided in the Supplementary Material.

In conclusion, awareness of research fraud is growing and there are important regional differences as shown in this overview. Moreover, a large quantity of retracted papers dealt with first-line ovulation induction treatment outcomes, either with or without adjuvant supplements. The majority of retracted papers were retracted during

the last decade, and there is apparently a tendency for publishers and journal editorial boards not to retract older papers. We should be aware of these findings when developing guidelines that provide recommendations for diagnosis, screening, treatmentand long-term health issues of PMOS.

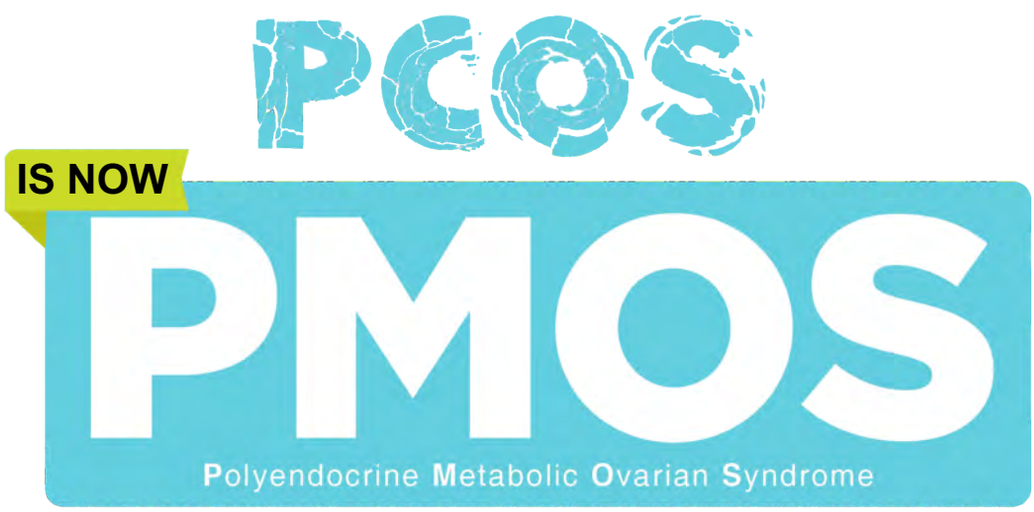
References:

1: Mousa A, Flanagan M, Tay CT, Norman RJ, Costello M, Li W, Wang R, Teede H,Mol BW. Research Integrity in Guidelines and evIDence synthesis (RIGID): a framework for assessing research integrity in guideline development and evidence synthesis. Eclinical Medicine. 2024 Jul 16;74:102717

Supplementary Material: Retracted Papers

Please click the link below to access the full list of retracted papers.

https://drive.google.com/file/d/1fBMoFGq8NDX06rHBVn8FHiABCoRR9jYL/view?usp=sharing



INTRODUCING NEW BOARD MEMBERS

Lisa Moran

Leads the Healthy Lifestyle Research Program

Monash Centre for Health Research and Implementation

Monash University, AUSTRALIA

A partnership between: MCHRI Monash Centre for Health Research and Implementation | MONASH University | Monash Health

Email:Lisa.Moran@monash.edu
Home page: https://mchri.org.au/about-mchri/our-people/lisa-moran/

Professor Moran leads the Healthy Lifestyle Research Program within the Monash Centre for Health Research and Implementation, Monash University. She is a research dietitian, Accredited Practicing Dietitian and clinical dietitian at Monash Health and an Affiliate staff member of the Robinson Research Institute at the University of Adelaide. She works in clinical, epidemiological and implementation nutrition research and clinical dietetics.

Her research skills include clinical trials, epidemiology and evidence-based medicine. Her area of interest is optimizing weight management and nutritional status in women of reproductive age with the aim of reducing the impact of obesity-related disease in women and their families. Her specific areas of research within this field include working with women with conditions including infertility, polycystic ovary syndrome (PCOS) and cardiometabolic complications during pregnancy. It also includes working with women across key life stages for targeting lifestyle interventions including preconception, during pregnancy and post-partum.

She specifically focuses on clinically translatable interventions, reducing attrition, effective components within lifestyle interventions and mechanisms for action. By developing optimal obesity intervention methods for Australian women, her research will result in a reduced risk of pregnancy complications, reduced side-effects of conditions such as PCOS including diabetes, heart disease and depression and provide a foundation to secure a healthier future for newborn children.

Check out some of her recent publications below!

- Perceived Risk Perception of Future Cardiovascular Disease and Diabetes in the Postpartum Period
- Childhood Sleep Behaviours and Polycystic Ovary Syndrome Risk in Adolescence: The Raine Study Cohort Longitudinal Study
- A Pilot Randomized Control Trial Evaluating the Feasibility of a 12-Week Mediterranean Diet Intervention Without Caloric Restriction in Women with Polycystic Ovary Syndrome
- Understanding barriers and facilitators to lifestyle management in people with polycystic ovary syndrome: A mixed method systematic review
- Translating evidence into practice in primary care management of adolescents and women with polycystic ovary syndrome: a mixed-methods study

Michael O'Reilly

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Michael O'Reilly is a Consultant Endocrinologist in Beaumont Hospital, Dublin, and Clinical Associate Professor at the Royal College of Surgeons in Ireland (RCSI). He is an honours graduate of National University of Ireland Galway (2005). His Clinical PhD fellowship into androgen metabolism in women was funded by the Wellcome Trust from 2012 to 2015 at the University of Birmingham under the supervision of Professor Wiebke Arlt. Upon completion of his PhD and specialist training, he was appointed as a Hoffenberg Clinician Scientist at the University of Birmingham and Honorary Consultant Endocrinologist at University Hospital Birmingham. He returned to a consultant post in Ireland in 2019. In 2020 he received a prestigious 4-year Emerging Clinician Scientist Fellowship from the Health Research Board of Ireland to fund his research into the role of 11-oxygenated androgens in metabolic disease in women. His group utilize innovative models to dissect the mechanisms of androgen-related metabolic disease including 3D bioprinting of skeletal muscle and in vivo stable isotope studies. He recently led a Society for Endocrinology Clinical Practice Guideline into the evaluation of severe androgen excess in women. His clinical interests include polycystic ovary syndrome, adrenal tumours and congenital adrenal hyperplasia.

Check out some of his recent publications below!

Factors affecting the quality of life of adults living with congenital adrenal hyperplasia: a qualitative study of lived experience.

James KL, Parkin N, Elford S, McKnight C, Phillips R, Pickles T, Ahmed SF, Krone N, Llahana S, O'Reilly MW, Tomlinson JW, Rees DA.Endocr Connect. 2026 May 12;15(5):e260033. doi: 10.1530/EC-26-0033. Print 2026 May 1.PMID: 42023589 Free PMC article.

Androgen receptor localisation and protein interactions provide insight into steroid mediated metabolic shifts in endocrine resistant breast cancer.

Bleach R, Bozkurt E, Xin J, Sheehan KM, Shirran S, Agbana S, Ola M, Young L, Spoelstra NS, Richer JK, Vargas AC, Goldstein LD, Milloli HH, Chaffer CL, O'Reilly MW, Prehn JH, McIlroy M.NPJ Breast Cancer. 2026 Mar 17;12(1):65. doi: 10.1038/s41523-026-00924-1.PMID: 41844688

Hepatic metabolism of 11-oxygenated androgens in humans: an integrated in vivo and ex vivo approach.

McDonnell T, Anthony AV, Clarke G, Schiffer L, Taylor AE, Cussen L, Fan Y, Hann A, Mao J, Shaheen F, Miller C, McIlroy M, Jacob B, Sherlock M, Afford SC, Storbeck KH, Arlt W, O'Reilly MW.Eur J Endocrinol. 2025 Aug 29;193(3):340-347. doi: 10.1093/ejendo/lvaf166.PMID: 40795393

Society for Endocrinology Clinical Practice Guideline for the Evaluation of Androgen Excess in Women.

Elhassan YS, Hawley JM, Cussen L, Abbara A, Clarke SA, Kempegowda P, Dhillon-Smith RK, Thadani P, Busby M, Owusu-Darkwah L, Marrington R, Duncan WC, Semple RK, Quinton R, O'Reilly MW.Clin Endocrinol (Oxf). 2025 Oct;103(4):540-566. doi: 10.1111/cen.15265. Epub 2025 May 13.PMID: 40364581

Impaired 11β-Hydroxysteroid Dehydrogenase Type 2 Activity in Kidney Disease Disrupts 11-Oxygenated Androgen Biosynthesis.

Tomkins M, McDonnell T, Cussen L, Sagmeister MS, Oestlund I, Shaheen F, Harper L, Hardy RS, Taylor AE, Gilligan LC, Arlt W, McIlroy M, de Freitas D, Conlon P, Magee C, Denton M, O'Seaghdha C, Snoep JL, Storbeck KH, Sherlock M, O'Reilly MW.J Clin Endocrinol Metab. 2025 May 19;110(6):1701-1715. doi: 10.1210/clinem/dgae714.PMID: 39382395

SCANDINAVIAN CONSUMER ENGAGEMENT GROUPS

Involvement and advocacy are necessary for meaningful change

By Ann Helen Brendehaug, *Executive Director PMOS Norway*

PMOS Norway is a recently established patient organization dedicated to promoting social equality and full participation for individuals living with PMOS. Founded in 2021, the organization opened for membership in 2023 and received its first public funding in 2025. It is currently led by a full-time Executive Director supported by a Board of Directors. Our organization is experiencing rapid growth and now represents 1,600 members.

As PMOS Norway has gained visibility among patients, healthcare professionals, public authorities, and the media, the demand for our user involvement and advocacy has increased significantly. We provide essential support to the patient community through peer-support initiatives and evidence based information. We contribute user perspectives to research, policy development, and public awareness efforts. Our overarching objectives are earlier diagnosis, expanded treatment options, and improved lifelong follow-up. Our members consistently report insufficient knowledge within primary healthcare and limited support for lifestyle-related interventions. We are committed to helping address these gaps.

In Norway, individuals with symptoms indicative of PMOS typically first consult their general practitioner (GP). Strengthening knowledge and training within primary healthcare has therefore been a strategic priority. In 2025, the Norwegian Medical Association awarded support for a digital training program for GPs, developed by Professor Eszter Vanky and GP specialist Bente Prytz Mjølstad at the Norwegian University of Science and Technology (NTNU), in collaboration with PMOS Norway. The program consists of an accredited continuing-education course covering diagnosis, treatment, and fertility, as well as follow-up across life stages and mental health. PMOS Norway's close collaboration with NTNU strengthens knowledge and understanding between lived experience and clinical practice, an advancement long requested by our members.

PMOS Norway has also contributed to the development of a digital self-management program for individuals with PMOS. The initiative is led by the private company TiltLab under the direction of Kaja Koppang, in collaboration with Professor Anne Lund and Associate Professor Fanny Alexandra Jakobsen at Oslo Metropolitan University, with support from the private foundation Dam. The project exemplifies how diverse stakeholders can collaborate to address unmet needs. The program aims to provide knowledge, coping strategies, and support while facilitating more individualized and interdisciplinary care within the health care system.

Our long-term ambition is to ensure that all individuals with PMOS can achieve and maintain good health throughout their lives. Raising awareness is a critical first step, and we have brought this issue directly to the Minister of Health. This spring, we are meeting with all political parties in Parliament to advocate for increased organizational funding and the establishment of national guidelines for PMOS diagnosis and

From left to right: Professor Eszter Vanky, Executive Director Ann Helen Brendehaug, Health Minister Jan Christian Vestre, Board member Regine Vinnes

treatment. Collaboration with national and international partners is essential to addressing systemic challenges. In May, we hosted patient organizations from Finland and Iceland for a Nordic exchange of experiences, supported by the Nordic Welfare Centre. This autumn we are initiating a European patient advocacy collaboration to highlight the need for more research on treatment approaches, including the potential use of GLP-1 therapies for PMOS.

As a young patient organization, we see clearly that user involvement and advocacy are both effective and necessary for meaningful change. We are actively advocating for the establishment of a Swedish and Danish patient organization and welcome further international collaboration.

We invite interested partners to engage with us through our online presence at www.pcosnorge.no or to reach out via email to annhelen@pcosnorge.no.

From left to right: Peer supporters Christel Fuss Olaisen and Therese Jansson

Gynaecological Patient Organisation In Finland Korentory: Nordic PMOS Patient Organisations Met In Oslo To Plan Patient Advocacy Collaboration

By: Olga Haapa-aho, *Executive director*

The patient organisations from three different Nordic countries met in Oslo at the beginning of May. I'm using the term PMOS patient organisations, although we are all still officially PCOS organisations, but we are getting used to the new name of the syndrome.

Although the health care systems vary between countries, there are many shared experiences among PMOS patients across the Nordic region. The Nordic Welfare Centre approved a grant to enable a meeting between Nordic patient organisations. The objective

of the meeting was to learn more about each other's work in PMOS patient advocacy. This time, we were able to connect active patient organisations from Norway, Finland, and Iceland. In the future, we hope to reach representatives from more Nordic countries to join our co-operation network. We are also looking forward to collaborating with patient organisations from other countries.

We held workshops to identify the biggest challenges for patients living with PMOS today. We found many shared challenges, but we wanted to highlight only the most important ones. Lack of knowledge was one of the main problems faced in the Nordic countries. For example, in a survey conducted in Iceland, 58.5 percent of respondents answered "not satisfied" or "no information" to the question "How satisfied were you with the information you were given when you were diagnosed?" As representatives of the patientorganisations, we were also concerned that the syndrome is too often seen only as a fertility problem. Fortunately, the new name highlights the metabolic and hormonal features of the syndrome The patient organisations from three different Nordic countries met in Oslo at the beginning of May. I'm using the term PMOS patient organisations, although we are all still officially PCOS organisations, but we are getting used to the new name of the syndrome.

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We also shared concerns about the effects of delays in diagnosis. In a Finnish patient organisation's survey, the average delay in receiving a diagnosis was nine years after first contacting health care professionals about symptoms. A delayed diagnosis can have multiple effects, for example on a patient's quality of life, associated conditions, and fertility. That is why we also discussed how patient organisations could help ensure earlier PMOS diagnoses. Providing materials and information is an important part of our work. Helping people living with PMOS recognise possible symptoms can encourage them to seek professional help earlier.

As important as providing information to people with symptoms is influencing the health care system. Many patients have experienced that general practitioners lack knowledge about PMOS. It is important to identify symptoms earlier, because many patients feel their symptoms have been ignored or dismissed. We learned from Norway's experience with a project aimed at increasing knowledge and competence among GPs in diagnosing and treating PMOS through an online education programme. Hopefully, we can develop more of these kinds of programmes in different countries in co-operation with patient organisations and medical professionals specialised in PMOS.

Society for Endocrinology Clinical Practice Guideline for the Evaluation of Androgen Excess in Women.

Elhassan YS, Hawley JM, Cussen L, Abbara A, Clarke SA, Kempegowda P, Dhillon-Smith RK, Thadani P, Busby M, Owusu-Darkwah L, Marrington R, Duncan WC, Semple RK, Quinton R, O'Reilly MW.Clin Endocrinol (Oxf). 2025 Oct;103(4):540-566. doi: 10.1111/cen.15265. Epub 2025 May 13.PMID: 40364581

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EC-SIG CORNER

EARLY CAREER SPECIAL INTEREST GROUP

By Hannah Lamar

The EC-SIG community invites early career professions who are interested in androgen excess disorders and PMOS to engage in community with supportive peers who share this same interest. The EC-SIG environment fosters professional growth and collaboration between EC-SIG members through various ways including:

1. In-person mentorship and leadership events at the AE-PCOS Annual Meetings where you will hear from experts across the field of androgen excess disorders and PMOS who share about their career and offer encouragement and guidance to trainees and early career professionals.
2. Quarterly meetings hosted via Zoom throughout each year where EC-SIG members will share about the research they are conducting and offer a time for the group to ask questions and learn deeper about their work.
3. Meet the Professor sessions hosted via Zoom which give the opportunity for you to hear from experts in androgen excess disorders and PMOS around the world about their specific areas of research.

If you are interested in joining the EC-SIG community, please contact aepcos.ecsig@gmail.com

2026 Leadership Committee

Faculty Mentor:
Melanie Cree

Chairs:
Jamie Benham and Tina Gorsek

EC-SIG Highlights

Update Meeting EC-SIG Meet & Greet

Following the AE-PCOS Update Meeting hosted in Prague this past May, the EC-SIG group met for an informal gathering at a local restaurant. This shared meal helped built comradery among the group, provided a space for continued conversation after the sessions presented at the Update Meeting, and offered time to build collaborations among members.

EC-SIG recently had the joy of inviting Professor Michael O'Reilly to speak with us at the April Meet the Professor event. Dr. O'Reilly is a Consultant Endocrinologist at Beaumont Hospital, Dublin and an Associate Professor in the Department of Medicine at the Royal College of Surgeons in Ireland and we had the privilege of learning about his research in adrenal tumors, female androgen excess, and Cushing's syndrome.

The recent AE-PCOS Meet the Professor with Professor Michael O'Reilly.

Upcoming EC-SIG Events

Be on the look our for an invitation to the next virtual Meet the Professor session to engage with one another and learn about special topics within androgen excess and PMOS from leading scientists.

We look forward to seeing everyone at the upcoming AE-PCOS Annual Meeting in December. We will be hosting a Meet & Greet, Mentorship Event, and Leadership Event at this conference and warmly invite you all to join us for vibrant and intentional conversation with one another. Stay tuned to hear more about these events as the conference nears!

FORMER CO-EDITORS' MESSAGE

Working as Newsletter Editor for AEPCOS has been a true pleasure. One of the highlights of the COVID era for me was the opportunity to engage virtually with the AEPCOS conference and eSIG, which represented my first introduction to this community from Canada. After later having the opportunity to meet these research leaders in Rotterdam, I was excited to become more involved. Since then, I have greatly enjoyed connecting with experts from around the world to highlight their important contributions to the PCOS now PMOS community. It has been rewarding to help showcase the breadth of innovation and expertise across our field. I am excited for the next editors to take on this role and look forward to seeing how the newsletter continues to grow and evolve in the years ahead.

All the best,

Alyse Goldberg MD FRCPC
University of Toronto, Canada

It has been a pleasure to serve as a co-Editor of the AEPCOS newsletter. I joined the team shortly after attending my first AEPCOS conference in Anaheim, California in 2022, and it has been great to learn about the Society and the amazing work happening in PCOS research, care, and advocacy from members around the world. I look forward to continuing with the AEPCOS Society as the EC-SIG Co-Chair.

Jamie Laura Benham, *MD PhD FRCPC*
University of Calgary, Canada

INTRODUCING NEW EDITORIAL TEAM

Dr. Sujata Kar is a practicing gynaecologist in Odisha for almost three decades.

After completing her MBBS & MD , with seven gold medals, Dr. Kar completed her DNB from the National Board and then pursued her advanced training in laparoscopic surgery and IVF in multiple national and international centers. She has been credited with many firsts in her state. Her areas of interest are PCOS, and proteomics of male fertility.

She has been an active executive member of multiple national academic bodies.She is currently the Vice president of the Indian Society for Assisted reproduction.

Abbey Kalay is a third-year PhD candidate at Cornell University under the mentorship of Dr. Marla Lujan. Her research uses ultrasound to study ovarian morphology in both normative populations and women with PCOS, with the goal of advancing understanding of ovarian physiology. She is especially interested in how ovarian morphology changes across the menstrual cycle and how these dynamic changes may affect diagnostic criteria. Abbey is excited to contribute to the AE-PCOS newsletter and engage with the broader PCOS research community.

Hannah Lamar is a PhD student in the Department of Nutrition at Texas A&M University where she studies the physiology of female reproductive maturation, ovarian antral follicle wave dynamics, and the role of the gut microbiome and bile acid metabolism under the mentorship of Dr. Heidi Vanden Brink.

Hannah is honored to contribute to this community of scientists through co-editing the newsletter and highlighting the amazing work being conducted within AE-PCOS.

CALENDAR OF EVENTS

2026 AE-PCOS 24th Annual Meeting

Date:
December 10–12, 2026

Location:
Kittilä, Finland

Abstract Submissions Are Now Open
Submission Deadline: 31 July 2026

ENDO 2026

Date: **June 13–16, 2026**

Location: **McCormick Place West, Chicago, Illinois, USA**

ASRM 2026 – ASRM Scientific Congress & Expo

Date: **October 24–28, 2026**

Location: **Baltimore, Maryland, USA**

ESHRE Annual Meeting 2026

Date: **5–8 July 2026**

Location: **London, United Kingdom**

Update Meeting

Date: **4 June 2027**

Location: **Toronto, Canada**

CALL FOR NEWSLETTER CONTENT

Want to be featured in next issue?
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"

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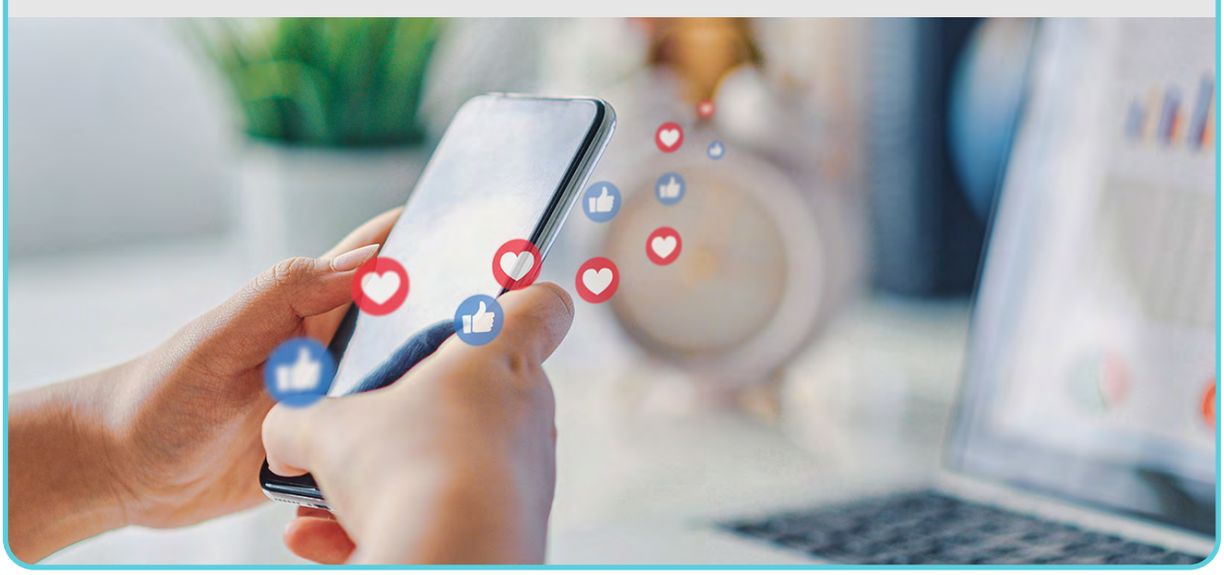
Our AEPCOS society has several social media accounts!
Please follow us on

aepocossociety @aepcossociety

Androgen Excess & Polycystic Ovary Syndrome

Androgen Excess & Polycystic Ovary Syndrome Society



AE-PCOS

24th Annual meeting,

December 10-12, 2026

Kittilä - Lapland - Finland