

PCOS Parent Survey

Thank you for your interest in this study. Your participation in this survey is voluntary. The purpose of this research survey is to better understand the experiences and needs of patients with polycystic ovary syndrome (PCOS). If you agree to participate, we will ask you to complete the survey either online or on paper. It is estimated that it will take approximately 10 minutes to complete the questions. You are also invited to complete a section with your comments. It is up to you how much time you wish to spend on the comments section.

In order to protect your confidentiality, the survey does not include any of your personal identifying information. If you have any questions, please feel free to contact Dr. Daniel Dumesic or a member of his study team by email at uclaobgynresearch@mednet.ucla.edu or by phone at (310) 825-0580. If you have any questions regarding research at UCLA, please feel free to contact the UCLA Office of the Human Research Protection Program (OHRPP) by phone at (310) 825-5344; by email at mirb@research.ucla.edu; or US mail at UCLA OHRPP, 11000 Kinross Ave, Suite 211, Box 951694, Los Angeles, CA 90095-1694. The confidentiality of emails cannot be guaranteed. Please do not include any sensitive information in email communications.

Only parents who have a daughter (of any age) that has been diagnosed with PCOS are eligible to complete this survey.

[] By checking this box, I am providing my assurance that I am the parent of a daughter (of any age) that has been diagnosed with PCOS.

1. At what age (in years) did your daughter first begin experiencing symptoms of PCOS?
 1. <10
 2. 10-15
 3. 16-25
 4. 26-35
 5. >36

2. Is your daughter presently experiencing any of the following symptoms? (indicate all that apply)
 1. Irregular menstrual periods
 2. Excessive facial or body hair
 3. Acne
 4. Excess weight gain
 5. Infertility
 6. None of the above

3. Has your daughter received a formal diagnosis of PCOS by a health care professional?
 1. Yes
 2. No
 3. Not Sure

4. If yes, how old was your daughter (in years) when she was first diagnosed with PCOS?
 1. <10
 2. 10-15
 3. 16-25
 4. 26-35
 5. 36+

5. What was the specialty of the doctor who diagnosed your daughter with PCOS?
 1. Family Practice
 2. Internal Medicine
 3. Medical Endocrinologist
 4. Obstetrician/Gynecologist
 5. Pediatrician
 6. Pediatric Endocrinologist
 7. Reproductive Endocrinologist
 8. Other

6. How many doctors did your daughter see for her symptoms before she received a diagnosis of PCOS?
 1. 1
 2. 2
 3. 3
 4. 4
 5. 5
 6. 6 or more

7. Did your daughter receive a pelvic ultrasound at the time of her diagnosis?
 1. Yes
 2. No
 3. Not Sure

8. Did your daughter receive a blood test for male hormone levels at the time of her diagnosis?
 1. Yes
 2. No
 3. Not Sure

9. At the time of her diagnosis, how satisfied were you with the explanation your daughter received about the cause of PCOS?
 1. Completely satisfied
 2. Mostly satisfied
 3. Satisfied
 4. Not Satisfied

10. At the time of your daughter's diagnosis, how satisfied were you with the initial explanation of the treatment options for managing her PCOS symptoms?
 1. Completely satisfied
 2. Mostly satisfied
 3. Satisfied
 4. Not Satisfied

11. Is your daughter presently taking any of the following prescription drugs to treat her PCOS symptoms? (indicate all that apply)
 1. Birth control pills
 2. Progestins (including Mirena IUD)
 3. Insulin sensitizers (i.e. metformin or glitazones)
 4. Spironolactone
 5. Anabolic steroids
 5. Blood pressure medications
 6. Cholesterol-lowering medications

12. Is your daughter presently using any interventions for removal of facial or body hair (i.e. creams, laser hair removal, electrolysis)?
 1. Yes
 2. No

13. At the present time, how satisfied are you with the medical care your daughter is receiving for management of her PCOS?
 1. Completely satisfied
 2. Mostly satisfied
 3. Satisfied
 4. Not Satisfied

14. Since your daughter's diagnosis, has she sought medical care for PCOS from a health care provider other than the one who diagnosed her PCOS?
 1. Yes
 2. No

15. What is your daughter's race?
 1. American Indian or Alaska Native
 2. East Asian
 3. South Asian
 4. Black or African American
 5. Native Hawaiian or other Pacific Islander
 6. Caucasian
 7. Mixed
 8. Other

16. What is your daughter's ethnic background?
 1. Hispanic or Latino (Latina?)
 2. Not Hispanic or Latino (Latina?)

17. What is your daughter's current age (years)?
 1. <17
 2. 18-25
 3. 26-35
 4. 36-50
 5. 51+

18. In what state does your daughter live?_____

19. Has your daughter searched the internet for information about PCOS?
 1. Yes
 2. No
 3. Don't know

20. Has your daughter joined an in-person PCOS support group?
 1. Yes
 2. No
 3. Don't know

21. If yes, how many in-person PCOS support groups, has your daughter joined?
 1. 1
 2. 2
 3. 3
 4. 4
 5. 5 or more
 6. Don't know

22. Has your daughter joined an online PCOS support group or forum?

1. Yes
2. No
3. Don't know

23. If yes, how many online support groups has your daughter joined?

1. 1
2. 2
3. 3
4. 4
5. 5 or more
6. Don't know

24. Have **you** searched the internet for information about PCOS?

1. Yes
2. No

25. Have **you** joined an in-person PCOS support group?

1. Yes
2. No

26. If yes, how many in-person PCOS support groups, have **you** joined?

1. 1
2. 2
3. 3
4. 4
5. 5 or more

27. Have **you** joined an online PCOS support group or forum?

1. Yes
2. No

28. If yes, how many online support groups have **you** joined?

1. 1
2. 2
3. 3
4. 4
5. 5 or more

COMMENTS: Please let us know how you think the health care system could be improved to better support PCOS patients (space is limited to 2000 characters including spaces)

If you would like to know if your daughter qualifies for a research study, please feel free to contact us by email at uclaobgynresearch@mednet.ucla.edu or by phone at (310) 825-0580. The confidentiality of emails cannot be guaranteed. Please do not include any sensitive information in email communications.

Thank you for taking the time to participate in this survey!

To return this survey by mail, please send to:

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