

## Appendix 1 - Lupus and Reproductive Health – English Survey

**Survey purpose:** Lupus is a chronic disease that can affect many parts of a person's life. Lupus can affect how women use contraception and experience pregnancy. Your experience with these issues is very valuable. We hope to use this survey to understand how we can improve our care of female lupus patients, especially for those who want to use contraception or become pregnant.

***Please only take this if you are female, between the ages of 18 – 50, and have been told that you have systemic lupus erythematosus (lupus)***

### Where do you receive the majority of your lupus care?

- LAC+USC Rheumatology Clinic
- Harbor UCLA Rheumatology Clinic
- Other: \_\_\_\_\_

### 1. How old are you? \_\_\_\_\_

### 2. What is your race?

- White
- Black/African American
- Asian American
- American Indian/Alaska Native
- Native Hawaiian/Pacific Islander
- Mixed race
- Prefer not to state
- Other (please write): \_\_\_\_\_

### 3. What is your ethnicity?

- Hispanic
- Non-Hispanic
- Prefer not to state

### 4. In what language do you prefer to receive your medical care?

- English
- Spanish
- Other (please write): \_\_\_\_\_

### 5. Education level:

- Less than high school
- High school diploma or equivalent

- Technical/vocational training
- Bachelor's degree
- Master's degree or above

**6. Marital status:**

- Never married
- Married, or in a domestic partnership
- Widowed
- Divorced or separated
- Prefer not to state

**7. Place of birth:**

- United States
- Outside the United States

**8. Religious affiliation:**

- Catholic
- Any denomination of Christianity other than Catholic
- Other religious group (please list): \_\_\_\_\_
- No religious affiliation

**9. Please select the following that best describes you:**

- I have never been sexually active with a male partner
- I have been sexually active with a male partner, but I am not currently sexually active with a male partner
- I am sexually active with a male partner, and I am currently trying to get pregnant
- I am sexually active with a male partner, and I am currently trying to AVOID a pregnancy
- I am sexually active with a male partner, and am neither trying to get pregnant nor trying to avoid it

**10. I use the following for contraception (please select all that apply):**

- Abstinence; or I'm not sexually active with a male partner
- Natural methods (pull out methods, fertility awareness)
- Barrier or spermicidal methods (condoms, spermicide, cervical cap or diaphragm)
- Short-acting birth control (oral contraceptive pills, vaginal ring, injection, patch)
- Long-acting reversible birth control (intrauterine device [IUD], hormonal implant)
- Sterilization (tubal ligation, hysterectomy, vasectomy, or post-menopausal)
- None – I don't use any type of contraception

**11. How many...**

**Times have you been pregnant? \_\_\_\_\_**

**How many miscarriages have you had? \_\_\_\_\_**

**How many elective (also called medical or surgical ) abortions have you had? \_\_\_\_\_**

**12. Which of the following medications are you currently taking? (please select all that apply):**

- Steroids (prednisone, methylprednisolone [Medrol])
- Hydroxychloroquine (Plaquenil)
- Mycophenolate mofetil (CellCept) or mycophenolic acid (Myfortic)
- Azathioprine (Imuran)
- Methotrexate (Rheumatrex)
- Leflunomide (Arava)
- Tacrolimus (Prograf)
- Voclosporin (Lupkynis)
- An injection or infusion in the past 3 months (belimumab [Benlysta], anifrolumab [Saphnelo], tocilizumab [Actemra], abatacept [Orencia])
- Rituximab (Rituxan) infusion in the past 6 months
- Cyclophosphamide (Cytoxan) infusion in the past 3 months
- An ACE inhibitor (benazepril, lisinopril, or captopril) or ARB (losartan, valsartan) blood pressure medicine
- NSAIDs (ibuprofen, naproxen, indomethacin, celecoxib, aspirin)
- I don't know
- None
- Other (please write): \_\_\_\_\_

***Please answer the following questions as it relates to your lupus doctor and you:***

**13. In the past one year, my lupus doctor has had at least one discussion regarding contraception with me.**

- Yes**
- No**

**14. My lupus doctor has explained what type of contraception I should or should not use in light of my lupus.**

- Yes
- No

**15. In the past one year, my lupus doctor has asked what my plans are, if any, for pregnancy**

- Yes
- No

***Questions 17 – 23 ONLY populate if patient answers in the affirmative to Question 16 “Yes, AFTER I was diagnosed with lupus”***

**16. Have you every been pregnant or have you ever tried to become pregnant? Choose all that apply.**

- Yes, BEFORE I was diagnosed with lupus
- Yes, AFTER I was diagnosed with lupus
- No

**17. My lupus doctor has told me that it’s important that my lupus is in remission before becoming pregnant**

- Yes
- No

**18. My lupus doctor has explained which medications I should continue when I’m trying to become pregnant or when I’m pregnant**

- Yes
- No

**19. My lupus doctor has told me that I should take hydroxychloroquine (Plaquenil) when I’m trying to become pregnant or when I’m pregnant**

- Yes
- No

**20. I took hydroxychloroquine (Plaquenil) during pregnancy or when I was trying to get pregnant**

- Yes, I was already on it and continued it while I was trying to get pregnant or during my pregnancy**
- Yes, I was not already on it, but I started it during this time**
- No, I stopped taking it when I found out I was pregnant or when I was trying to get pregnant**
- No, I was not taking it and did not start it at this time**
- Other**

**21. My lupus doctor has explained which medications I should NOT continue during a pregnancy or if I'm trying to get pregnant**

- Yes**
- No**

**22. My lupus doctor has checked my blood for lupus-related risk factors that might make me or my baby at high risk during a pregnancy**

- Yes**
- No**
- I don't know**

**23. My lupus doctor has explained which medications are safe to take during breastfeeding**

- Yes**
- No**

**24. My lupus doctor has enough information to answer questions I have about lupus and its effect on contraception or pregnancy**

- Yes**
- No**

**25. What makes it hard to discuss contraception and pregnancy questions with your lupus doctor? Please choose all that apply.**

- We don't have enough time in my appointment
- My lupus doctor has suggested that I talk with an OB-GYN instead
- There is a language barrier between my doctor and me
- I don't think my lupus doctor knows enough about contraception or pregnancy issues
- I don't feel comfortable talking about these issues with my lupus doctor
- I don't think it's safe for me to become pregnant
- I don't think these topics are relevant or important to me
- Other (please write): \_\_\_\_\_
- None

**26. Who is most likely to initiate a conversation about reproductive health-related topics during an appointment with my lupus doctor?**

- I am
- My lupus doctor is
- My lupus doctor and I are equally likely to initiate a conversation about reproductive health-related topics
- My lupus doctor and I have never discussed reproductive health-related topics

**27. Where do you get most of your information regarding lupus and reproductive health? Please choose the top three.**

- My OB-GYN
- My lupus doctor
- Another doctor
- Significant other
- Family member
- Friends
- Lupus support group
- Information found on an internet site
- Social media
- Television
- Other (please write): \_\_\_\_\_

**28. Please let us know anything else that's important to you regarding reproductive health:**

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