

Marfan Syndrome Survey

A Note On Privacy

This survey is anonymous.

The record kept of your survey responses does not contain any identifying information about you. Please do not write in any identifying information. Please do not write your identifying information on the return envelope. There is no way of matching your identity with responses in this survey.

Instructions:

1. Please answer all of the questions to the best of your ability.
2. Some of the questions require fill-in-the-blank answers; when doing so, please write in your answer legibly.
3. For other questions you will need to check-mark the answer(s).
4. If you are under 18 years of age, please read the consent form carefully and ask permission from your parent or guardian to participate.
5. Please answer the questions by yourself.
6. Please do not skip any questions that apply to you.
7. Please do not write your name or provide any other identifying information on the questionnaire

Little information is available in scientific literature on contraception practices and recommendations for men or women affected by the Marfan syndrome (MFS). There is also little information on association of Marfan syndrome and pelvic connective tissue disorders.

You have been selected for participation in this survey because you have told the National Marfan Foundation that you, or a close relative of yours, have MFS. We would like to ask your kind participation, whether a man or a woman, in this survey on pregnancy and contraception issues in MFS. There is no right or wrong answers; we are merely interested in what you know and what medical professionals have told you. Your answers will elucidate the need for and inspire future investigations in issues related to MFS.

These questions and the multiple choice answers are not meant to suggest medical advice. Please do not write your name or provide any other identifying information on the questionnaire. Please choose ALL answers that apply. The survey is in 3 parts and takes less than 14 minutes on average to answer all questions. Part 3, connective tissue disorders (of pelvic organs), applies only to females.

On behalf of National Marfan Foundation and Stanford University we thank you for your participation. Once we have completed the project and analyzed the results we will be pleased to share the results with you. The results are expected to be available by early 2009 and will be posted on Vesta Research Company web site. To request a copy of the results, please send a separate e-mail to:

MFS Survey
M. Mark Taslimi, M.D.
Marfan.Stanford@VestaGate.com

Sincerely,

Contraception, Pregnancy, and Connective Tissue Disorder in Marfan Syndrome Research Group at Stanford University
David Liang, MD; Mary Jacobson, MD; Bertha Chen, MD; Kasra Navabi, MD; Kenneth Hunter, DPA; M Mark Taslimi, MD.

Consent to participate in study

I agree to participate in Marfan Syndrome Survey and give my permission to the researchers at Stanford Marfan Center to include the following anonymous information provided by me in their analysis and publication of the results.

I declare that I am 18 years of age or older

I declare that I am under 18 years of age and I have my parent's or guardian's permission to participate in this survey by completing and mailing this survey I declare my agreement to participate in this survey

There are a maximum of 52 questions in this survey. You may have fewer questions based on your demographic information.

Consent for participant younger than 18 years of age

(Please read carefully if you are under 18 years of age)

Dear participant,

We are required to obtain the following consent to participate in this survey because you have told us that you are younger than 18 years of age. Please read the following brief consent form and click on the next button below if you are agree to participate in this survey.

1. Explanation of the Study (What will happen to me in this study?) - You will respond to a series of questions related to your knowledge of pregnancy and contraception related issues in patients with Marfan syndrome.
2. Risks or Discomforts of Participating in the Study (Can anything bad happen to me?) - There are no risks expected for participation in this study.
3. Benefits of Participating in the Study (Can anything good happen to me?) - There are direct benefits to you. The information learned will benefit Marfan patients by encouraging more research on Marfan syndrome.
4. Confidentiality (Will anyone know I am in the study?) - No, this study is completely anonymous.
5. Contact Information (Who can I talk to about the study?) - You can send a confidential letter to the principal investigator at the address below.
6. Voluntary Participation (What if I do not want to do this?) - You may decline to participate as well.

BY COMPLETING AND MAILING THIS SURVEY I DECLARE THAT I UNDERSTAND THIS STUDY AND I AM WILLING TO PARTICIPATE IN SURVEY. ALSO, I HAVE MY PARENT'S OR GUARDIAN'S PERMISSION TO PARTICIPATE IN THIS SURVEY.

Your Demographics

1: I am _____ years of age this year.

2: I weigh _____ pounds or _____ kilograms.

3: My height is _____ inches or _____ centimeters.

4: I have Marfan syndrome.

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '4')

5: I was diagnosed with Marfan syndrome when I was _____ years of age.

6: Does your spouse/partner(s) have Marfan syndrome?

Please choose *only one* of the following:

- Yes
- No
- I do not know
- Does not apply

7: Do your parent(s) have Marfan syndrome?

Please choose *only one* of the following:

- Yes
- No
- I do not know
- Does not apply

8: Do any of your children have Marfan syndrome?

Please choose *only one* of the following:

- Yes
- No
- I do not know
- Does not apply

9: Do any of your brothers or sisters have Marfan syndrome?

Please choose *only one* of the following:

- Yes
- No
- I do not know

Does not apply

10: Are any of the above relatives with Marfan answering this survey?

Please choose *only one* of the following:

Yes

No

I do not know

Does not apply

11: I am a:

Please choose *only one* of the following:

Female

Male

Pregnancy and contraception

(If you are a male, please go to questions number 20)

12: I am currently pregnant.

Please choose **only one** of the following:

- Yes
- No
- Do not know
- Do not apply

13: I have been previously pregnant.

Please choose **only one** of the following:

- Yes
- No
- Do not know
- Do not apply

(If you DID NOT answered 'Yes' to question '13 ', please go to questions number 20)

14: How many pregnancies have you had (present or past)?

Please write your answer here:

15: How many previous live births have you experienced?

Please write your answer here:

16: How many vaginal deliveries have you had?

Please write your answer here:

17: How many cesarean sections have you had?

Please write your answer here:

18: How many early miscarriages or pregnancy terminations (before 20 weeks/five months) have you experienced?

Please write your answer here:

19: How many late pregnancy losses have you experienced?

Please write your answer here:

20: How many living children (regardless of age) do you have?

Please write your answer here:

21: I believe women who have Marfan can have a safe pregnancy:

Please choose the appropriate response for each item:

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree
Safety of pregnancy in Marfan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22: Which of the following statements characterize what physicians have told you about pregnancy and Marfan syndrome?

Please choose *all* that apply:

- A woman can have a safe pregnancy even if she has Marfan syndrome
- A woman cannot have a safe pregnancy if she has Marfan syndrome
- Other factors besides Marfan syndrome determine the safety of the pregnancy
- A man or a woman with Marfan syndrome should not have children

Other:

(If you are a male, this is the end of your survey, Thank you for your participation; If you are a female, please answer the following questions.)

23: Doctor(s) have discussed contraception issues with me:

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '23')

24: Did the physician provide you with information on contraception in Marfan?

Please choose the appropriate response for each item:

	Never	Occasionally	Several times	Without you asking	Only when you asked
Being informed by physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25: How would you characterize the frequency of your conversations with your physician(s) about contraception?

Please choose *only one* of the following:

- I have had only 1 conversation with my physician about contraception
- I have had only 2 conversations with my physician(s) about contraception
- I have had more than 2 conversations with my physician(s) about contraception
- I cannot recall how many conversations I have had with my physician(s) about contraception

26: I have had ___ with my physician(s) about contraception.

Please choose *only one* of the following:

- No conversation
- Only 1 conversation
- Only 2 conversations

More than 2 conversations

27: What method(s) of contraception your physician(s) stated are appropriated for a woman with Marfan syndrome?

Please choose *all* that apply:

- Birth control pills
- Birth control shots
- Birth control skin patches
- Birth control implants
- Male or female condoms
- Diaphragm
- IUD
- Abstinence
- Male or female permanent sterilization surgery

Other:

28: Did your physician(s) provide you with information on menstrual cycles in Marfan?

Please choose the appropriate response for each item:

	Never	Occasionally	Several times	Without you asking	Only when you asked
Being informed by physician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

29: I would characterize my menstrual periods as:

Please choose the appropriate response for each item:

	Heavy	Moderate	Light
Menstrual characteristic	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

30: I have been diagnosed with anemia.

Please choose *only one* of the following:

- Yes
- No

Female connective tissue disorders

Note: Please make sure you have answered the pregnancy questions part of the survey and continue with this part

31: Have you had a hysterectomy (surgical removal of the uterus)?

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '31')

32: At what age have you had a hysterectomy (surgical removal of the uterus)?

Please write your answer here:

33: Have you had surgery for treatment of urinary incontinence?

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '33')

34: After surgery for treatment of urinary incontinence your symptoms:

Please choose *only one* of the following:

- Remain unchanged
- Improve
- Worsen
- Improve at first but recurred after a while

35: Have you had surgery for treatment of uterine or vaginal prolapse?

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '35')

36: After surgery for treatment of uterine or vaginal prolapse your symptoms:

Please choose *only one* of the following:

- Remain unchanged
- Improve
- Worsen
- Improve at first but recurred after a while

37: Do you have a bulge or something falling out that you can see or feel in the vaginal area?

Please choose *only one* of the following:

Yes

No

(Only answer this question if you answered 'Yes' to question '37')

38: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39: Do you have to push on the vagina or around the rectum to have or complete a bowel movement?

Please choose *only one* of the following:

Yes

No

(Only answer this question if you answered 'Yes' to question '39')

40: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

41: Do you experience a feeling of incomplete bladder emptying?

Please choose *only one* of the following:

Yes

No

(Only answer this question if you answered 'Yes' to question '41')

42: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

43: Do you ever have to push up on a bulge in the vaginal area with your fingers to start or complete urination?

Please choose *only one* of the following:

Yes

No

(Only answer this question if you answered 'Yes' to question '43')

44: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

45: Do you experience frequent urination?

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '45 ')

46: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

47: Do you experience urine leakage associated with a feeling of urgency (that is, a strong sensation of needing to go to the bathroom)?

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '47 ')

48: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

49: Do you experience urine leakage related to coughing, sneezing, or laughing?

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '49 ')

50: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

51: Do you experience small amounts of urine leakage (that is, drops)?

Please choose *only one* of the following:

- Yes
- No

(Only answer this question if you answered 'Yes' to question '51 ')

52: How much does this bother you?

Please choose the appropriate response for each item:

	Not at all	Somewhat	Moderately	Quite a bit	Not applicable
Bothersome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please Mail Your Survey in the Provided Envelope.

Thank you for completing this survey.