

# Supplementary File 1

## Survey

1. How old were you when you were diagnosed with Marfan's syndrome?
2. Do you have any of the following features of Marfan's syndrome?
  - Do you have lens dislocation?
  - Do you have a known mutation in fibrillin 1 (*FBN1*) gene?
  - Do you have a family history of Marfan's syndrome?
  - Do you or did you have an aortic aneurysm?
  - Do you have a family history of aortic dissection?
  - Do you have these skeletal features of Marfan's syndrome?
    - i. Scoliosis
    - ii. Wrist or thumb sign
    - iii. Pectus excavatum or carinatum (chest asymmetry)
    - iv. Pes planus (flat feet)
3. Have you ever had surgery to repair your aorta?
  - a. How old were you at the age of surgery?
  - b. Was the surgery performed after you had an aortic dissection (tear in the aorta)?
  - c. If you did *NOT* have a valve sparing procedure, what kind of composite valve graft did you have?
    - Biological (tissue/pig/cow) valve
    - Mechanical (metal valve)
  - d. Have you ever been pregnant? If no→ SKIP TO COUNSELING QUESTIONS
    - i. How many pregnancies did you have *BEFORE* having aortic surgery?
      - What was outcome of each pregnancy?
        - a. Full term delivery (delivery after 37 weeks)
        - b. Pre term delivery (delivery before 37 weeks)
        - c. Miscarriage (unintentional delivery before 24 weeks)
        - d. Elective abortion
        - e. Stillborn
      - What type of delivery did you have?
        - a. Vaginal
        - b. Cesarean
      - What type of anesthesia did you have?
        - a. Epidural
        - b. General
        - c. None
      - Did you have an aortic dissection (tear in the aorta) related to your pregnancy? If so, when did this occur?
        - a. During the first trimester
        - b. During the second trimester
        - c. During the third trimester
        - d. During labor and delivery
        - e. 2 weeks after delivery
        - f. 2 to 4 weeks after delivery
        - g. Greater than 4 weeks after delivery
        - h. I did not have an aortic dissection
      - Did you have high blood pressure prior to becoming pregnant?
        - a. Yes
        - b. No
      - Did you develop high blood pressure during pregnancy, after 20 weeks of pregnancy (i.e., gestational hypertension)?
        - a. Yes
        - b. No

- Did you have any of the following complications during pregnancy?
    - a. Pre-eclampsia or toxemia
    - b. Eclampsia (seizure)
    - c. I did not have any of these complications
  - Did you take a  $\beta$ -blocker (i.e., atenolol, propranolol, metoprolol) during this pregnancy?
    - a. Yes
    - b. No
  - Did you take a calcium channel blocker during pregnancy (i.e., amlodipine, diltiazem, verapamil)?
    - a. Yes
    - b. No
  - Did you smoke during this pregnancy?
    - a. Yes
    - b. No
  - Did you take any of the following blood thinners during pregnancy?
    - a. Aspirin
    - b. Coumadin
    - c. Lovenox
    - d. I did not take any blood thinners during pregnancy
  - Did you breast feed for at least 2 weeks after delivery?
    - a. Yes
    - b. No
  - Was this an unintended pregnancy?
    - a. Yes
    - b. No
- ii. How many pregnancies did you have *AFTER* having aortic surgery?
- What was outcome of pregnancy each pregnancy?
    - a. Full term delivery (delivery after 37 weeks)
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## Counseling

1. Did your doctor recommend against pregnancy due to the high maternal risk and fetal abnormalities associated with pregnancy in Marfan's syndrome?
  - a. Yes
  - b. No
2. Were you counseled on the risk of having an aortic dissection related to pregnancy *AFTER* undergoing aortic surgery?
  - a. Yes
  - b. No
3. Were you told that despite having undergone prior aortic surgery, you would continue to be at high risk for an aortic dissection related to pregnancy?
  - a. Yes
  - b. No