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)
  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 labor and delivery
  b. 2 weeks after delivery
  c. 2 to 4 weeks after delivery
  d. Greater than 4 weeks after delivery
  e. 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 (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 β-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 breastfeed for at least 2 weeks after delivery?
  a. Yes
  b. No

• Was this an unintended pregnancy?
  a. Yes
  b. No

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