

Experiences of Women Living with PD - Fertility, Pregnancy, and Childbirth

This is the third survey in a series focused on women's health. This survey is designed to gather information about the reproductive health of women with Parkinson's before and after diagnosis. There is very little known about how or if Parkinson's impacts fertility, pregnancy and birth. We appreciate your time and thoughtful answering of the survey questions. We understand that for many women in Fox Insight, answering this survey may be difficult when the events occurred many years in the past. We welcome you to provide any information possible, regardless of pregnancy history. We also understand that your medical history is sensitive and private information. All answers will remain confidential. Please remember that you do not need to answer any questions that make you uncomfortable. Thank you for being a part of this groundbreaking work.

Establishing a Parkinson's only, female only cohort

Multiple choice, single answer, required

1. What sex were you assigned at birth, on your original birth certificate?
 - a. Male
 - b. Female
 - c. Prefer not to answer

Multiple choice, single answer, required

2. What is your current gender identity?
 - a. Male

Display Logic: If (a. Male) or is selected for "What sex were you assigned at birth, on your original birth certificate?".

- b. Female

Display Logic: If (b. Female) is selected for "What sex were you assigned at birth, on your original birth certificate?".

- c. Transgender male

Display Logic: If (b. Female) is selected for "What sex were you assigned at birth, on your original birth certificate?".

- d. Transgender female

Display Logic: If (a. Male) is selected for "What sex were you assigned at birth, on your original birth certificate?".

- e. Other (gender non-conforming, genderqueer, non-binary, etc.)
 - f. Not sure
 - g. Prefer not to answer

Skip Logic: If (a. Male) is selected for "What is your current gender identity?", skip to End of Survey thank you 1.

Skip Logic: If (a. Male) is selected for "What sex were you assigned at birth, on your original birth certificate?" AND (d. Transgender female), (e. Other), (f. Not sure), or (g. Prefer not to answer) is selected for "What is your current gender identity?", skip to End of Survey thank you 2.

Multiple choice, single answer, required

3. Have you been diagnosed with Parkinson's disease?
- a. Yes, I have been diagnosed with Parkinson's disease
 - b. No, I have not been diagnosed with Parkinson's disease

Skip Logic: If (b. No) is selected, then skip to End of survey thank you 3.

Text entry, required

4. What year were you diagnosed with Parkinson's disease?

Fertility

Multiple choice, single answer, required

5.0 Have you ever seen a doctor due to difficulty getting pregnant?

- a. Yes
- b. No
- c. Prefer not to answer

Skip Logic: If (a. Yes) is NOT selected, skip to 6.0

Multiple choice, single answer, required

5.1 Did the doctor tell you why you were unable to get pregnant?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

5.2 What reasons did the doctor give you to explain why you were unable to get pregnant? Please select all that apply:

- a. Problem with your partner's fertility
- b. Problem with your hormones
- c. Problem with your fallopian tubes or uterus
- d. Endometriosis
- e. Immune-related issues
- f. They were unable to find a problem
- g. Not sure
- h. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did the doctor tell you why you were unable to get pregnant?"

Multiple choice, multiple answer, required

5.3 As a treatment for infertility, which of the following have you used? Please select all that apply.

- a. In vitro fertilization
- b. Infertility medications
- c. Intrauterine insemination
- d. Egg donation

- e. Surgical treatment (e.g. for endometriosis)
- f. I chose not to undergo treatments for infertility
- g. Other
- h. Not sure
- i. Prefer not to answer

Multiple choice, multiple answer, required

6.0 From whom did you seek advice about fertility? Please select all that apply.

- a. I sought advice from my Ob/gyn
- b. I sought advice from my primary care provider (e.g. family doctor)
- c. I sought advice from my Parkinson's nurse
- d. I sought advice from my neurologist/movement disorders specialist
- e. I sought advice from a genetic counselor
- f. I sought advice from family, friends and/or partner
- g. I did not seek advice about fertility
- h. Other
- i. Prefer not to answer

Multiple choice, single answer, required

7.0 At any point during your reproductive years did you refrain from becoming pregnant due to your Parkinson's diagnosis? Please select the best option.

- a. Yes
- b. No
- d. Prefer not to answer

Multiple choice, multiple answer, required

7.1. What was your reason for refraining from pregnancy? Please select all that apply.

- a. Concern that my Parkinson's would worsen with pregnancy
- b. Concerns about possible dangers to the baby
- c. Concerns about taking Parkinson's medication during pregnancy
- d. Pressure from partner, family or friends not to get pregnant
- e. There was no longer a desire to have children
- f. I wanted to have children but was unable to become pregnant
- g. I had concerns about parenting in the long term
- h. I was advised not to get pregnant by a medical professional
- i. Concerns about genetic inheritance
- j. Other
- k. Prefer not to answer

Display Logic: If (a. Yes) is selected for "At any point during your reproductive years did you refrain from becoming pregnant due to your Parkinson's diagnosis?"

Multiple choice, multiple answer, required

8.0 Have you ever chosen to terminate a pregnancy or were advised to on medical grounds?

- a. Yes, before my Parkinson's diagnosis
- b. Yes, after my Parkinson's diagnosis
- c. No

d. Prefer not to answer

Multiple choice, single answer, required

8.1. How many times have you chosen or have been advised to terminate a pregnancy?

- a. 1 time
- b. 2 times
- c. 3 times
- d. 4 times
- e. More than 4 times
- f. Prefer not to answer

Display Logic: If (a.) or (b.) is selected for "Have you ever chosen to terminate a pregnancy or were advised to on medical grounds?"

Genetics/Screening

Multiple choice, single answer, required

9.0 Have you undergone genetic testing for variants related to Parkinson's disease? Examples include testing in the LRRK2, GBA (also associated with Gaucher disease), Parkin, Pink1, and/or alpha-synuclein (SNCA) genes.

- a. Yes
- b. No
- c. Prefer not to answer

Skip Logic: If (a. Yes) is NOT selected, skip to 10.0

Multiple choice, single answer, required

9.1 Were you advised to see a genetic counselor?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

9.2 Did you see a genetic counselor?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

9.3 Were you found to have a variant in a gene related to Parkinson's disease?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Skip Logic: If (a. Yes) is NOT selected, skip to 10.0

Multiple choice, single answer, required

9.4 Was the variant in any of the following genes? Please select all that apply.

- a. LRRK2,
- b. GBA (also associated with Gaucher disease),
- c. Parkin,
- d. Pink1
- e. alpha-synuclein (SNCA) genes
- f. Other
- g. Not sure
- h. Prefer not to answer

Multiple choice, single answer, required

9.5 Did the counseling regarding your positive Parkinson's gene screening influence your decision to conceive?

- a. Yes
- b. No
- c. Prefer not to answer

Display logic: If (a. Yes) is selected for "Did you see a genetic counselor?"

Pregnancy status

Multiple choice, multiple answer, required

10.0 Have you ever been pregnant?

- a. Yes
- c. No, but desired pregnancy
- d. No, due to Parkinson's
- e. No, due to other reason
- f. Prefer not to answer

Skip Logic: If (c.), (d.), (e.), or (f.) is selected, then skip to the End of Survey

Text box, number only, required

10.1 How many times have you been pregnant **before** your Parkinson's diagnosis? This includes all pregnancies (livebirth, ectopic pregnancy, medical or spontaneous abortion, etc)

Number of times pregnant before Parkinson's diagnosis: ____

Skip Logic: If 0 times, then skip to 32

Questions 11-31 will loop according to the answer selected in 10.1 for pregnancies before PD dx

Multiple choice, single answer, required

11 Which of the following best describes your [1st, 2nd, 3rd, etc] pregnancy before your Parkinson's diagnosis?

- a. Had liveborn baby
- b. Pregnancy but no live birth (i.e. ectopic pregnancy, medical or spontaneous abortion)

Skip Logic: If (b. Pregnancy but no live birth) is selected, skip to 29

Multiple choice, single answer, required

12. In retrospect, when do you think your initial Parkinson's symptoms appeared?

- a. Before this pregnancy
- b. During this pregnancy
- c. After this pregnancy
- d. Not sure
- e. Prefer not to answer

LIVEBIRTH BEFORE DIAGNOSIS

Multiple choice, multiple answer, required

13 Who cared for you during this pregnancy? Please select all that apply.

- a. a midwife
- b. nurse practitioner
- c. a family doctor/or primary care provider
- d. OB/GYN
- e. a neurologist
- f. Movement disorders specialist
- g. Maternal fetal medicine doctor
- h. Parkinson's nurse
- i. Other
- j. Prefer not to answer

Multiple choice, single answer, required

13.1 Were you advised to see a genetic counselor during this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, single answer, required

14. Was this pregnancy planned?

- a. Yes
- b. No
- c. Prefer not to answer

Text entry, not required

15. What was your age during delivery? Please make your answer a number only. If you prefer not to answer, you may leave this question blank.

Age during delivery: ____

Text entry, not required

16. What was the birth weight of the baby for this pregnancy? If you are not sure, please make your best guess. If you prefer not to answer, you may skip this question.

Sliding scale: ____ lbs and oz

Text entry, not required

17. What was the gestational age at delivery for this pregnancy? Please provide the answer in **weeks** and **days**, if known. If you are not sure, please make your best guess. If you prefer not to answer, you may skip this question.

Sliding scale: ____

Multiple choice, single answer, required

18. Were there any abnormal findings on ultrasounds of the baby before birth?

- a. Yes
- b. No
- c. Not performed
- d. Prefer not to answer

Skip logic: If (a. Yes) is NOT selected, then skip to 19 "Was this pregnancy considered to be high risk?"

Multiple choice, multiple answer, required

18.1 What were the findings of the ultrasound? Please select all that apply.

- a. Anatomical anomaly (something concerning with development of baby)
- b. Growth restriction (baby measuring small)
- c. Large for gestational age (baby measuring large)
- d. Too little amniotic fluid
- e. Too much amniotic fluid
- f. Other
- g. Not sure
- h. Prefer not to answer

Text entry, required

18.2 What anatomical anomaly was found in the ultrasound? If you do not know or prefer not to answer, you may leave this question blank.

Text box: ____

Display logic: If (a. Anatomical anomaly) is selected for "What were the findings of the ultrasound?"

Multiple choice, single answer, required

19. Was this pregnancy considered to be high risk?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

19.1 Why was your pregnancy considered high risk? Please select all that apply.

- a. Because of my Parkinson's
- b. Because of a previous complicated pregnancy and birth
- c. Because of my age
- d. Concerns about my health (e.g. preeclampsia, diabetes, etc)
- e. Fetal surveillance (concern about the baby)
- f. Other
- g. Not sure
- h. Prefer not to answer

Display logic: If (a. Yes) is selected for "Was your pregnancy considered to be high risk?"

Multiple choice, single answer, required

20. Was your labor induced?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

20.1 Why was your labor induced? Please select all that apply.

- a. Post-term pregnancy
- b. Gestational diabetes
- c. Advanced maternal age (mother 35 years of age or older at delivery)
- d. Gestational hypertension
- e. Pre-eclampsia
- f. Elective
- g. Because of Parkinson's
- h. Because of concern for the baby
- i. Other
- j. Prefer not to answer

Display logic: If (a. Yes) is selected for "Was your labor induced?"

Multiple choice, single answer, required

21. What type of delivery did you have?

- a. Vaginal delivery
- b. Instrumented vaginal delivery (vacuum or forceps delivery)
- c. Caesarian section
- d. VBAC (vaginal birth after Cesarian)
- e. Prefer not to answer

Multiple choice, single answer, required

21.1 What was the reason for your caesarian section?

- a. Elective,
- b. Fetal distress,
- c. Pre-eclampsia
- d. Failed induction of labor,
- e. Failure to progress,
- f. Second stage arrest (unable to push baby out),

- g. Breech or compound presentation
- h. Placenta previa,
- i. Placental abruption,
- j. Other
- k. Prefer not to answer

Display logic: If (c. Caesarian section) is selected for "What type of delivery did you have?"

Multiple choice, single answer, required

22. Did you experience any complications during pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

22.1 Which of the following did you experience during pregnancy? Please select all that apply.

- a. Elevated blood pressure
- b. Preeclampsia
- c. Gestational diabetes
- d. Infections
- e. Placenta previa
- f. Cervical insufficiency
- g. Preterm birth
- h. Depression
- i. Other
- j. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you experience any complications during pregnancy?"

Multiple choice, single answer, required

23. Did you experience any complications during delivery?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

23.1 What complications did you experience during delivery? Please select all that apply.

- a. Hemorrhage(excessive bleeding)
- b. Preterm labor
- c. Preterm delivery (before 37 weeks gestation)
- d. Infection
- e. Fetal distress
- f. Other
- g. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you experience any complications during delivery?"

Multiple choice, single answer, required

24. Did you experience any complications **up to one year** after delivery?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

24.1 What complications did you experience after delivery? Please select all that apply.

- a. Uterine Infection
- b. Excessive blood loss/bleeding, hemorrhage
- c. Breast problems (swelling, blocked milk ducts, infection)
- d. Hemorrhoids
- e. Constipation
- f. Incontinence
- g. Anxiety symptoms
- h. Postpartum depression or psychosis requiring treatment
- i. Other
- j. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you experience any complications after delivery?"

Multiple choice, single answer, required

25. Were there any complications for the baby during labor, delivery or at birth?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, multiple answer, required

25.1 What were the complications? Please select all that apply.

- a. fetal distress during labor baby stayed with mom after delivery
- b. fetal distress during labor and baby admitted to neonatal intensive care unit (NICU)
- c. no fetal distress during labor and baby admitted to neonatal intensive care (NICU) after delivery
- d. Other
- e. Not sure
- f. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Were there any complications for the baby during labor, delivery or at birth?"

Multiple choice, single answer, required

26. Did you breast feed?

- a. Yes

- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

26.1 Why didn't you breastfeed? Please select all that apply.

- a. Advised by medical provider
- b. Symptoms of PD interfered with process
- c. Concerns about medication and breastfeeding
- d. Failure to latch on
- e. Breast infection
- f. Personal choice
- g. Other
- h. Prefer not to answer

Display Logic: If (b. No) is selected for "Did you breast feed?"

Multiple choice, single answer, required

27. Were you diagnosed with a postpartum mood disorder often described as "post-natal depression"?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

27.1 Were you prescribed medication for postpartum mood disorder (post-natal depression)?

- a. Yes
- b. No
- c. Prefer not to answer

Display logic: If (a. Yes) is selected for "Were you diagnosed with a postpartum mood disorder often described as "post-natal depression"?"

Multiple choice, multiple answer, required

27.2 Which medication did you take? Please select all that apply.

- a. SSRI (Zoloft, Celexa, Lexapro, Prozac)
- b. SNRI (Wellbutrin, Effexor)
- c. anti-anxiety (Buspar, Valium, Ativan, Xanax)
- d. Other
- e. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Were you prescribed medication for postpartum mood disorder (post-natal depression)?"

Multiple choice, single answer, required

28. Were you hospitalized with postpartum psychosis?

- a. Yes
- b. No
- c. Prefer not to answer

Skip logic: If this question is displayed, then skip to end of block

Now we will ask about your next reported pregnancy prior to your Parkinson's diagnosis.

[Skip to here if (b. Pregnancy but no live birth) is selected for Q11]

29. At what time point during your pregnancy did this pregnancy loss occur?
- a. Less than 10 weeks
 - b. 10-20 weeks
 - c. After 20 weeks until 7 days after birth
 - d. I don't know
 - e. Prefer not to answer

Multiple choice, single answer, required

30. Did this pregnancy result in delivering a stillborn (pregnancy loss after 28 weeks)?
- a. Yes
 - b. No
 - c. Prefer not to answer

Display logic: If (c. After 20 weeks until 7 days after birth) is selected for "At what time point during your pregnancy did this pregnancy loss occur?"

31. Was this pregnancy an ectopic pregnancy (a pregnancy in the fallopian tube)?
- a. Yes
 - b. No
 - d. Prefer not to answer

Survey will loop back to 11 "Which of the following best describes your [1st, 2nd, 3rd, etc] pregnancy before your Parkinson's diagnosis?" after this question depending on how many pregnancies they've had.

LIVEBIRTH AFTER DIAGNOSIS

Multiple choice, single answer, required

32 How many times have you been pregnant **after** your Parkinson's diagnosis? This includes all pregnancies (livebirth, ectopic pregnancy, medical or spontaneous abortion, etc)

Number of times pregnant after Parkinson's diagnosis: ____

Skip logic: If 0 times, then skip to End of Survey

Questions 33-64 will loop according to the answer selected in Question 32 for pregnancies after PD dx

Multiple choice, single answer, required

33 Which of the following best describes your [1st, 2nd, 3rd, etc] pregnancy after your Parkinson's diagnosis?

- a. Had liveborn baby
- b. Pregnancy but no live birth (e.g. ectopic pregnancy, medical or spontaneous abortion)

Skip Logic: If (b. Pregnancy but no live birth) is selected, skip to 62

Multiple choice, multiple answer, required

34. After your Parkinson's diagnosis, who cared for you during this pregnancy? Please select all that apply.

- a. a midwife
- b. nurse practitioner
- c. a family doctor/or primary care provider
- d. OB/GYN
- e. a neurologist
- f. Movement disorders specialist
- g. Maternal fetal medicine doctor
- h. Parkinson's nurse
- i. Other
- j. Prefer not to answer

Multiple choice, single answer, required

35. Did the people caring for you during this pregnancy collaborate with the people caring for your Parkinson's?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

36. Were you taking any medications for Parkinson's disease before this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

36.1 Which medication/treatment did you take before this pregnancy? Please select all that apply.

- a. Carbidopa / Levodopa Immediate Release (Sinemet, Kinson, Dhivy)
- b. Carbidopa / Levodopa Controlled Release (Sinemet CR)
- c. Carbidopa / Levodopa Extended Release Capsules (Rytary, Numient, or Crexont)
- d. Carbidopa / Levodopa Inhalation Powder (Inbrija)
- e. Carbidopa / Levodopa and Entacapone (Stalevo)
- f. Other delivery systems (e.g. pump)

- g. Other Parkinson's medication
- h. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Were you taking any medications for Parkinson's disease before pregnancy?"

Multiple choice, single answer, required

37. Did you take Parkinson's medication after this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

37.1 Which medication/treatment did you take after this pregnancy? Please select all that apply.

- i. Carbidopa / Levodopa Immediate Release (Sinemet, Kinson, Dhivy)
- j. Carbidopa / Levodopa Controlled Release (Sinemet CR)
- k. Carbidopa / Levodopa Extended Release Capsules (Rytary, Numient, or Crexont)
- l. Carbidopa / Levodopa Inhalation Powder (Inbrija)
- m. Carbidopa / Levodopa and Entacapone (Stalevo)
- n. Other delivery systems (e.g. pump)
- o. Other Parkinson's medication
- p. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you take Parkinson's medication after this pregnancy?"

Multiple choice, single answer, required

38. Did you use any Parkinson's medication during this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

38.1 Which medication /treatment did you take during this pregnancy? Please select all that apply.

- a. Carbidopa / Levodopa Immediate Release (Sinemet, Kinson, Dhivy)
- b. Carbidopa / Levodopa Controlled Release (Sinemet CR)
- c. Carbidopa / Levodopa Extended Release Capsules (Rytary, Numient, or Crexont)
- d. Carbidopa / Levodopa Inhalation Powder (Inbrija)
- e. Carbidopa / Levodopa and Entacapone (Stalevo)
- f. Other delivery systems (e.g. pump)
- Other Parkinson's medication
- g. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you use any Parkinson's medication during pregnancy?"

Multiple choice, single answer, required

39. Did you have surgery or a procedure for treating Parkinson's disease before this pregnancy?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, multiple answer, required

39.1 Which of the following procedures for treating the symptoms of Parkinson's disease did you have before this pregnancy? Please select all that apply.

- a. Deep brain stimulation (DBS)
- b. Focused ultrasound (FUS)
- c. Thalamotomy
- d. Pallidotomy
- e. Other
- f. Not sure
- g. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Have you had surgery or a procedure for treating Parkinson's disease?"

Multiple choice, single answer, required

40. Did you stop your medication regimen for Parkinson's before or during this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Were you taking any medications for Parkinson's disease before this pregnancy?" OR for "Did you use any Parkinson's medication during this pregnancy?"

Skip Logic: If (b. No) or (c. Prefer not to answer) is selected, skip to "Did you start another medication during your pregnancy?"

Multiple choice, multiple answer, required

40.1 Why did you stop taking your Parkinson's medication before or during this pregnancy? Please select all that apply.

- a. Because I was pregnant
- b. Because I was advised to by obstetrician
- c. Because I was advised to by an OB provider
- d. Because I was advised to by a Parkinson's provider
- e. Because I was advised to by a peer
- f. Because I was planning on getting pregnant
- g. Because I was anxious
- h. Other
- i. Prefer not to answer

Multiple choice, multiple answer, required

40.2 Which Parkinson's medication(s) did you stop before or during this pregnancy?
Please select all that apply.

- a. Carbidopa / Levodopa Immediate Release (Sinemet, Kinson, Dhivy)
- b. Carbidopa / Levodopa Controlled Release (Sinemet CR)
- c. Carbidopa / Levodopa Extended Release Capsules (Rytary, Numient, or Crexont)
- d. Carbidopa / Levodopa Inhalation Powder (Inbrija)
- e. Carbidopa / Levodopa and Entacapone (Stalevo)
- f. Other delivery systems (e.g. pump)
- g. Other Parkinson's medication
- h. Prefer not to answer

Display logic: Answers chosen from questions 36.1 and 38.1 will be displayed as answer choices

Multiple choice, multiple answer, required

40.3 Did you start another medication during this pregnancy? Please select all that apply.

- a. No
- b. Carbidopa / Levodopa Immediate Release (Sinemet, Kinson, Dhivy)
- c. Carbidopa / Levodopa Controlled Release (Sinemet CR)
- d. Carbidopa / Levodopa Extended Release Capsules (Rytary, Numient, or Crexont)
- e. Carbidopa / Levodopa Inhalation Powder (Inbrija)
- f. Carbidopa / Levodopa and Entacapone (Stalevo)
- g. Other delivery systems (e.g. pump)
- h. Other Parkinson's medication
- i. Non-Parkinson's medication
- j. Prefer not to answer

Multiple choice, single answer, required

41. Did your Parkinson's symptoms impact this pregnancy?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, multiple answer, required

41.1 Which trimester was impacted by your Parkinson's symptoms for this pregnancy?
Please select all that apply.

- a. first trimester – conception to 12 weeks.
- b. second trimester – 13 to 27 weeks.
- c. third trimester – 28 to 42 weeks.
- d. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did your Parkinson's symptoms impact your pregnancy?"

Multiple choice, single answer, required

42. Did your Parkinson's symptoms change during this pregnancy?
- a. Yes, my symptoms improved
 - b. Yes, my symptoms worsened
 - c. No, my symptoms remained the same
 - d. Prefer not to answer

Multiple choice, single answer, required

43. Did your Parkinson's symptoms change **up to one year** after this pregnancy?
- a. Yes, my symptoms improved
 - b. Yes, my symptoms worsened
 - c. No, my symptoms remained the same
 - d. Prefer not to answer

Multiple choice, single answer, required

44. Was this pregnancy planned?
- a. Yes
 - b. No
 - c. Prefer not to answer

Text entry, not required

45. What was your age during delivery for this pregnancy? If you prefer not to answer, you may leave this question blank.

Age during delivery: ____

Slider graphic, not required

46. What was the birth weight of the baby for this pregnancy? If you are not sure, please make your best guess. If you prefer not to answer, you may leave this question blank.

Sliding scale: ____ Lbs and oz

Text entry, not required

47. What was the gestational age at delivery for this pregnancy? Please provide the answer in **weeks** and **days**, if known. If you are not sure, please make your best guess. If you prefer not to answer, you may leave this question blank.

Sliding scale: ____

Multiple choice, single answer, required

48. Were there any abnormal findings on ultrasounds of the baby before birth?
- a. Yes
 - b. No
 - c. Not performed
 - d. Prefer not to answer

Skip Logic: If (b. No), (c. Not performed), or (d. Prefer not to answer) is selected, skip to "Was this pregnancy considered to be high risk?"

Multiple choice, multiple answer, required

- 48.1 What were the findings of the ultrasound? Please select all that apply.

- a. Anatomical anomaly (something concerning the development of baby)
- b. Growth restriction (baby measuring small)
- c. Large for gestational age (baby measuring large)
- d. Too little amniotic fluid
- e. Too much amniotic fluid
- f. Other
- g. Not sure
- h. Prefer not to answer

Text entry, not required

48.2 What anatomical anomaly was found in the ultrasound? If you do not know or prefer not to answer, you may leave this question blank.

Text box: _____

Display Logic: If (a. Anatomical anomaly) is selected for "What were the findings of the ultrasound?"

Multiple choice, single answer, required

49. Was this pregnancy considered to be high risk?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

49.1 Why was this pregnancy considered high risk? Please select all that apply.

- a. Because of my Parkinson's
- b. Because of a previous complicated pregnancy and birth
- c. Because of my age
- d. Concerns about my health (e.g. preeclampsia, diabetes, etc)
- e. Fetal surveillance (concern about the baby)
- f. Other
- g. Not sure
- h. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Was your pregnancy considered to be high risk?"

Multiple choice, single answer, required

50. Was your labor induced for this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

50.1 Why was your labor induced? Please select all that apply.

- a. Post-term pregnancy
- b. Gestational diabetes
- c. Advanced maternal age (mother 35 years of age or older at delivery)
- d. Gestational hypertension

- e. Pre-eclampsia
- f. Elective
- g. Because of Parkinson's
- h. Because of concern for the baby
- i. Other
- j. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Was your labor induced?"

Multiple choice, single answer, required

51. What type of delivery did you have for this pregnancy?

- a. Vaginal delivery
- b. Instrumented vaginal delivery (vacuum or forceps delivery)
- c. Caesarian section
- d. VBAC (vaginal birth after Cesearian)
- e. Prefer not to answer

Multiple choice, single answer, required

51.1 What was the reason for your caesarian section?

- a. Elective,
- b. Fetal distress,
- c. Pre-eclampsia
- d. Failed induction of labor,
- e. Failure to progress,
- f. Second stage arrest (unable to push baby out),
- g. Breech or compound presentation
- h. Placenta previa,
- i. Placental abruption,
- j. Other
- k. Prefer not to answer

Display logic: If (c. Caesarian section) is selected for "What type of delivery did you have for this pregnancy?"

Multiple choice, single answer, required

52. Did you experience any complications during this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

52.1 Which of the following did you experience during this pregnancy? Please select all that apply.

- a. Elevated blood pressure
- b. Preeclampsia
- c. Gestational diabetes
- d. Infections
- e. Placenta previa
- f. Cervical insufficiency

- g. Preterm birth
- h. Depression
- i. Other
- j. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you experience any complications during pregnancy?"

Multiple choice, single answer, required

53. Did you experience any complications during delivery for this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

53.1 What complications did you experience during delivery? Please select all that apply.

- a. Hemorrhage(excessive bleeding)
- b. Preterm labor
- c. Preterm delivery (before 37 weeks gestation)
- d. Infection
- e. Fetal distress
- f. Other
- g. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you experience any complications during delivery?"

Multiple choice, single answer, required

54. Did you experience any complications after delivery for this pregnancy?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

54.1 What complications did you experience after delivery? Please select all that apply.

- a. Uterine Infection
- b. Excessive blood loss/bleeding, hemorrhage
- c. Breast problems (swelling, blocked milk ducts, infection)
- d. Hemorrhoids
- e. Constipation
- f. Incontinence
- g. Anxiety symptoms
- h. Postpartum depression or psychosis requiring treatment
- i. Other
- j. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you experience any complications after delivery?"

Multiple choice, single answer, required

55. Do you think your Parkinson's symptoms interfered with labor and delivery for this pregnancy?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

56. Did your labor and delivery for this pregnancy impact your Parkinson's symptoms?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

56.1 How did your labor and delivery impact your Parkinson's symptoms?

- a. My symptoms improved
- b. My symptoms worsened
- c. Not sure
- d. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did your labor and delivery impact your Parkinson's symptoms?"

Multiple choice, single answer, required

57. Were there any complications for the baby during labor, delivery or at birth for this pregnancy?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, multiple answer, required

57.1 What were the complications? Please select all that apply.

- a. fetal distress during labor (baby stayed with mom after delivery)
- b. fetal distress during labor and baby admitted to neonatal intensive care unit (NICU)
- c. no fetal distress during labor and baby admitted to neonatal intensive care (NICU) after delivery
- d. Not sure
- e. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Were there any complications for the baby during labor, delivery or at birth?"

Multiple choice, single answer, required

58. Did you breast feed this baby?

- a. Yes

- b. No
- c. Prefer not to answer

Skip Logic: If (b. No) or (c. Prefer not to answer) is selected, skip to "Why didn't you breastfeed this baby?"

Multiple choice, single answer, required

58.1 Did your Parkinson's symptoms impact your breastfeeding for this baby?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

58.2 Did your breastfeeding for this baby impact your Parkinson's symptoms?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Multiple choice, single answer, required

58.3 How did breastfeeding impact your Parkinson's symptoms?

- a. My symptoms improved
- b. My symptoms stayed the same
- c. My symptoms worsened
- d. Not sure
- e. Prefer not to answer

Display logic: if (a. Yes) is selected for "Did your breastfeeding for this baby impact your Parkinson's symptoms?"

Multiple choice, multiple answer, required

58.4 What Parkinson's medication did you use during breastfeeding for this baby?

Please select all that apply.

- a. I did not use any Parkinson's medication
- b. Carbidopa / Levodopa Immediate Release (Sinemet, Kinson, Dhivy)
- c. Carbidopa / Levodopa Controlled Release (Sinemet CR)
- d. Carbidopa / Levodopa Extended Release Capsules (Rytary, Numient, or Crexont)
- e. Carbidopa / Levodopa Inhalation Powder (Inbrija)
- f. Carbidopa / Levodopa and Entacapone (Stalevo)
- g. Other delivery systems (e.g. pump)
Other Parkinson's medication
- h. Prefer not to answer

Multiple choice, single answer, required

58.5 While breastfeeding, did you change your Parkinson's medication regimen or continue a medication change that began during pregnancy?

- a. Yes

- b. No
- c. Prefer not to answer

Display logic: If (a. I did not use any Parkinson's medication) is NOT selected for "What Parkinson's medication did you use during breastfeeding for this baby?"

Multiple choice, multiple answer, required

58.6 Why did you change your Parkinson's medication regimen while breastfeeding this baby? Please select all that apply.

- a. Because I was continuing a medication change that began during pregnancy
- b. Because I was advised to by an OB provider
- c. Because I was advised to by a Parkinson's provider
- d. Because I was advised to by a peer
- e. Because I was planning on getting pregnant again
- f. Because I was anxious about taking medication while breastfeeding
- g. Other
- h. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Did you change your medication regimen while you were breastfeeding?"

Multiple choice, multiple answer, required

59. Why didn't you breastfeed this baby? Please select all that apply.

- a. Advised by medical provider
- b. Symptoms of PD interfered with process
- c. Concerns about medication and breastfeeding
- d. Failure to latch on
- e. Breast infection
- f. Personal choice
- g. Other
- h. Prefer not to answer

Display Logic: If (b. No) is selected for "Did you breast feed?"

Multiple choice, single answer, required

60. Were you diagnosed with a postpartum mood disorder often described as "post-natal depression" after this pregnancy?

- a. Yes
- b. No
- c. Not sure
- d. Prefer not to answer

Skip Logic: If (b. No), (c. Not sure), or (d. Prefer not to answer) is selected, skip to B40

Multiple choice, single answer, required

60.1 Were you prescribed medication for postpartum mood disorder (post-natal depression)?

- a. Yes
- b. No
- c. Prefer not to answer

Multiple choice, multiple answer, required

60.2 Which medication did you take? Please select all that apply.

- a. SSRI (Zoloft, Celexa, Lexapro, Prozac)
- b. SNRI (Wellbutrin, Effexor)
- c. anti-anxiety (Buspar, Valium, Ativan, Xanax)
- d. Other
- e. Prefer not to answer

Display Logic: If (a. Yes) is selected for "Were you prescribed medication for postpartum mood disorder (post-natal depression)?"

Multiple choice, single answer, required

61. Were you hospitalized with postpartum psychosis after this delivery?

- a. Yes
- b. No
- c. Prefer not to answer

Now we will ask about your next reported pregnancy following your Parkinson's diagnosis.

[Skip to here if (b. Pregnancy but no live birth) is selected for Q33]

Multiple choice, single answer, required

62. At what time point during your pregnancy did this pregnancy loss occur?

- a. Less than 10 weeks
- b. 10-20 weeks
- c. After 20 weeks until 7 days after birth
- d. I don't know
- e. Prefer not to answer

Multiple choice, single answer, required

63. Did this pregnancy result in delivering a stillborn (pregnancy loss after 28 weeks)?

- a. Yes
- b. No
- c. Prefer not to answer

Display logic: If (c. After 20 weeks until 7 days after birth) is selected for "At what time point during your pregnancy did this pregnancy loss occur?"

Multiple choice, single answer, required

64. Was this pregnancy an ectopic pregnancy (a pregnancy in the fallopian tube)?

- a. Yes
- b. No
- d. Prefer not to answer

[Survey will loop back to 33 “Which of the following best describes your [1st, 2nd, 3rd, etc] pregnancy after your Parkinson's diagnosis?” after this question depending on how many pregnancies they've had.]

END OF SURVEY THANK YOU:

Thank you for taking part in this survey. Your answers will help us learn more about your experience with pregnancy while living with PD. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

End of Survey Thank You 1:

Thank you for participating in Fox Insight. This survey is currently only collecting responses from people whose gender identity is female. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

End of Survey thank you 2:

Thank you for participating in Fox Insight. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**

End of Survey thank you 3:

Thank you for participating in Fox Insight. This survey is currently only collecting responses from people who have been diagnosed with Parkinson's disease. We appreciate your interest in sharing your experiences. **Please click on the next arrow below (>>) to submit your responses and be redirected to the Fox Insight website.**