Transforming the Healthcare of Women with Cerebral Palsy

Weinberg Family Cerebral Palsy Center
New York-Presbyterian Hospital
Columbia University
Project Director: David P. Roye, MD
Project Coordinator: Rachel Jordan (rachel.jordan@cprif.org)

Rehabilitation Institute of Chicago
Northwestern University
Site Director: Deborah J. Gaebler-Spira, MD
Project Coordinator: Sara Jerousek (sjerousek@ric.org)

Boston Children’s Hospital
Harvard Medical School
Site Director: Laurie J. Glader, MD
Project Coordinator: TBA

UCLA Center for Cerebral Palsy
University of California at Los Angeles
Site Director: Eileen G. Fowler, PhD, PT
Project Coordinator: TBA

Funded and co-directed by the Cerebral Palsy International Research Foundation (CPIRF) with support from the 100 Women in Hedge Funds

For more information contact Rachel Jordan, Project Manager, at rachel.jordan@cprif.org

The purpose of this project is to improve the gynecological, reproductive, and breast healthcare women with cerebral palsy and related disabilities receive. Your responses to this survey will help medical researchers and healthcare providers understand your needs and concerns resulting in positive changes in the delivery of healthcare for women with disabilities. You may have assistance from another person to complete this survey.

You must be diagnosed with cerebral palsy and be 18 years-of-age or older to participate in this survey. Please note that all responses will remain CONFIDENTIAL. Thank you for your time!

This survey has been approved by the Columbia University Institutional Review Board (IRB) AAAO2304(Y1M01) on behalf of all participating sites.
If you agree to take part in this research, you will be asked to complete a survey that will take approximately 10-15 minutes. The survey is comprised of questions about gynecological, reproductive, and breast healthcare that you have received. Your responses to this survey will help medical researchers and healthcare providers understand your needs and concerns resulting in positive changes in the delivery of healthcare for women with disabilities. You may have assistance from another person to complete this survey.

Your responses are confidential and we are not collecting any identifying information.

If you have any questions about this research, please contact Rachel Jordan at 212-305-2700.

Please choose "Agree" and you will be taken to the survey. Please choose "Disagree" and you will be taken out of the survey.

Thank you again for sharing your experience.

☐ Agree
☐ Disagree
1. Who is completing this survey? (Please check all that apply)
   - Myself
   - Parent
   - Caregiver
   - Spouse/ Partner
   - Friend
   - Other (Please specify) ________________

   If this survey is being filled out by someone other than yourself please specify why:
   - I need physical help.
   - I need help understanding the questions.

2. Do you have Cerebral Palsy?
   - Yes
   - No

3. How old are you? ________________

4. What is your ethnicity?
   - Hispanic or Latino
   - Not Hispanic or Latino

5. What is your race? (Check all that apply.)
   - Asian
   - American Indian or Alaska Native
   - Black or African American
   - Native Hawaiian or Other Pacific Islander
   - White
   - Hispanic
   - Prefer not to answer.
   - Other, please specify ________________

-Continue to next page-
6. What is your highest level of education?
- Did not complete high school
- High school/ GED
- Some college
- Associate Degree
- Bachelor Degree
- Master Degree
- Advanced Graduate work or doctorate
- I don’t know

7. What is your current employment status?
- Employed for wages
- Self-employed
- Out of work and looking for work
- Out of work but not currently looking for work
- Homemaker
- Student
- Military
- Retired
- Unable to work
- I don’t know

8. Which category best describes your annual household income?
- Less than $24,999
- $25,000 to $49,999
- $50,000 to $99,999
- $100,000 or more
- I don’t know

9. What is your zip code? __________

10. Do you have health insurance? (Check all that apply.)
- No
- Yes, medicaid
- Yes, medicare
- Yes, private insurance
- I don’t know

-Continue to next page-
11. Please read the following and **mark only one box** beside the picture and description that best represents your movement abilities. The pictures are of men but should apply to everyone:

- You walk on your own without using aids, can go up and down stairs without using a handrail.

- You walk and climb stairs using a rail, and have difficulties walking on uneven or inclined surfaces or walking in crowds or confined spaces.

- You can walk on level surfaces using a walking aid (i.e. walker, rollator, crutches, canes etc.) but use a wheelchair to travel quicker or over longer distances.

- You can achieve self mobility with a powered wheelchair, but find it very hard to stand or walk without significant support.

- You have difficulty sitting on your own and controlling your head and body posture in most positions.

-Continue to next page-
12. Which statement best describes your ability to understand speech:
- I have no trouble understanding conversation
- I have minor difficulty understanding conversation
- I understand my name and short sentences, but I have a lot of difficulty understanding conversations
- I can respond to a voice, but I am unable to understand speech
- I cannot respond to voice and I am unable to understand speech
- I don’t know

13. Which statement best describes your speaking abilities:
- No difficulty speaking
- I speak with minor limitations
- I speak with some difficulty; my speech may be slow or somewhat difficult for a new listener to understand
- I speak with very significant difficulty; my speech is slow or very difficult for a new listener to understand
- I communicate using adapted techniques such as signing or an augmentative communication device
- My communication is severely limited even with the use of augmentative technology
- I don’t know

14. Which statement best describes your arm/hand function:
- I handle objects easily and successfully
- I handle most objects but with somewhat reduced quality and/or speed of achievement
- I handle objects with difficulty; need help to prepare and/or modify activities
- I handle a limited selection of easily managed objects in adapted situations
- I do not handle objects and have severely limited ability to perform even simple actions
- I don’t know

15. Do you have a primary/routine health care provider?
- No
- Yes, internist
- Yes, pediatrician
- Yes, Family/ General practitioner
- Yes, Nurse practitioner
- Yes, other: ____________________

-Continue to next page-
Gynecological Care
Refers to well woman care, diagnosis, and treatment of disorders of the female reproductive system including a pelvic exam.

16. Have you ever had a gynecological (pelvic) examination?
☐ Yes → Skip to Question 18
☐ No → Continue to Question 17

17. If you answered no, why have you NOT had a gynecological (pelvic) exam?
☐ No one ever recommended one
☐ Attempted, but not able to be completed. Why? ____________________
☐ I declined
☐ Too many doctor appointments already
☐ Fear of the procedure
☐ Other: ____________________

18. If you answered yes, who performed your gynecological exam?
☐ My primary care provider
☐ A gynecologist
☐ An obstetrician
☐ Other: ____________________
☐ I don't know

19. During your gynecological exam visit, what kinds of accommodations were available to help you? (Check all that apply.)
☐ Handicap parking close to office
☐ Ramps, elevator, wide doorways in office
☐ Assistance with completing forms
☐ Accessible changing area with bench or chair
☐ Dressing/undressing assistance
☐ Translator, sign language interpreter, or other communication aides (e.g. written or diagrammed materials)
☐ Positive attitude toward you as a person
☐ Exam table that goes up and down
☐ Transfer assistance
☐ I do not require any accommodations
☐ Other: ____________________

-Continue to next page-
20. What accommodations could have helped you during your visit? (Check all that apply.)
- Handicap parking close to office
- Ramps, elevator and/or wide doorways in the office
- Assistance with completing forms
- Accessible changing area with bench or chair
- Dressing/ undressing assistance
- Translator, sign language interpreter, or other communication aides (e.g. written or diagrammed materials)
- Positive attitude toward you as a person
- Exam table that goes up and down
- Transfer assistance
- I do not require any accommodations
- Other: ____________________

21. Have you received any of the following methods for a gynecological exam? (Check all that apply.)
- Specialized equipment (e.g. adaptive boot stirrups)
- Pre-procedure medication (sedative or muscle relaxant)
- Pre-visit anesthesia consultation
- Botulinum Toxin (BOTOX®) injections into leg muscles
- Alternate positioning to facilitate exam
- An exam without a speculum (instrument that is inserted into your vagina during exam)
- Other: ____________________
- None of the above
- I don’t know

22. Has your provider offered resources and/or told you about the following? (Check all that apply.)
- Cervical cancer prevention and screening (e.g. Pap smear)
- Breast self exams at home
- Sexually transmitted infection
- Reproductive health planning
- Birth control options
- Hormonal manipulation (regulating or preventing your period)
- None of the above
- I don’t know

-Continue to next page-
23. Have you had any of the following procedures during a gynecological exam? (Check all that apply.)
   ☑ Pap smear
   ☑ Physical breast examination by provider
   ☑ Sexually transmitted infection screening
   ☑ Prescription for birth control
   ☑ Treatment or prescription for hormonal manipulation (regulating or preventing your period)
   ☑ None of the above
   ☑ I don’t know

-Continue to next page-
**Sexuality and Sexual Health**

24. Before you were 18 years old, which, if any, did you ever talk with a parent or guardian about...? (ENTER all that apply.)
   - How to say no to sex
   - Methods of birth control
   - Where to get birth control
   - Sexually transmitted diseases
   - How to prevent HIV/AIDS
   - How to use a condom
   - None of the above

25. Have you talked with a health care provider about...? (ENTER all that apply.)
   - How to say no to sex
   - Methods of birth control
   - Where to get birth control
   - Sexually transmitted diseases
   - How to prevent HIV/AIDS
   - How to use a condom
   - None of the above

26. Has a health care provider ever offered you birth control?
   - Yes
   - No

-Continue to next page-
Human Papillomavirus (HPV) Vaccination.
Two vaccines, or shots to prevent HPV infection are available in the United States. Both vaccines prevent cervical cancer and one also prevents genital warts. The two HPV vaccines are sometimes called CERVARIX or GARDASIL.

27. Before this survey, have you ever heard of the HPV vaccines or shots?
○ Yes
○ No
○ Unsure

28. Have you ever received an HPV shot or vaccine?
○ Yes
○ No
○ Doctor refused when asked
○ Unsure

30. How many HPV shots did you receive? ________________

-Continue to next page-
Mammogram and Breast Health care.
A mammogram is an x-ray picture of the breast to check for breast cancer in women who may or may not have signs or symptoms of the disease.

31. Have you ever had a mammogram and/or breast ultrasound?
   - Yes – Mammogram → Skip to Question 33.
   - Yes - Breast ultrasound → Skip to Question 33.
   - No → Continue to Question 32.

32. If no, why have you NOT had a mammogram?
   - Never ordered or recommended by a health care provider
   - Attempted, but was unable to complete due to my disability
   - I declined because too many doctor appointments already
   - I declined because of fear of the procedure
   - I declined because I don't think that I am at risk for breast cancer
   - I am under 40 years of age
   - Other: ____________________

33. Have you had a mammogram and/or breast ultrasound in the past two years?
   - Yes
   - No

34. What was the reason for having a mammogram and/or breast ultrasound?
   (Check all that apply.)
   - Routine screening (no problem with your breasts)
   - To evaluate a lump or other problems with your breast
   - Family history of breast cancer
   - Personal history of breast
   - I don't know

35. When scheduling your mammogram and/or breast ultrasound, did the facility ask if you needed assistance for your exam?
   - Yes
   - No

-Continue to next page-
36. At your last mammogram and/or breast ultrasound, what kinds of accommodations were available to help you? (Check all that apply.)
- Handicap parking close to the office
- Ramps, elevator and/or wide doorways in office
- Positive attitude toward you as a person
- Assistance with completing forms
- Accessible area with bench or chair
- Transfer assistance
- Dressing/undressing assistance
- An explanation of what would take place in the examinations
- Translator, sign language interpreter or other communication aides (e.g. written or diagrammed materials)
- Allowing own personal care assistant to help, even if assistant is male (e.g. spouse/partner)
- Accessible mammogram machine
- Accommodations for wheelchair positioning
- Accommodations for difficulty with standing
- Accommodations for difficulty with positioning of the arm or shoulder
- Other: ____________________
- None of the above accommodations were available.
- I do not require any accommodations

37. At your last mammogram and/or breast ultrasound, what accommodations could have helped your exam? (Check all that apply.)
- Handicap parking close to the office
- Accessible office (e.g. ramps, elevator, wide doorways)
- Positive attitude toward you as a person
- Assistance with completing forms
- Accessible changing area with bench or chair
- Transfer assistance
- Dressing/Undressing assistance
- An explanation of what would take place in the examinations
- Translator, sign language interpreter or other communication aides (e.g. written or diagrammed materials)
- Allowing own personal care assistant to help, even if assistant is male (e.g. spouse/partner)
- Accessible mammogram machine
- Accommodations for wheelchair positioning
- Accommodations for difficulty with standing
- Accommodations for difficulty with positioning of the arm or shoulder
- Other: ____________________
- I do not require any accommodations

-Continue to next page-
Reproductive life planning, pregnancy, postpartum care

38. Has a health care provider ever asked you whether you want to have a child?
   - Yes
   - No
   - I don't know

39. Have you ever been pregnant?
   - Yes
   - No (Thank you, you have finished the survey.)

40. How many pregnancies have you had? ____________

41. What was the outcome of your pregnancy/pregnancies?
   - Full-term birth
   - Premature birth
   - Miscarriage
   - Stillbirth
   - Abortion/ Termination
   - Other: ____________________

42. If you have given birth to a child/ children, how did you deliver? (Check all that apply.)
   - Vaginal delivery
   - Cesarean delivery (C-Section)

43. Did any of your deliveries result in the following: (Check all that apply.)
   - Normal birth weight
   - Low birth weight (less than 5 1/2 pounds)
   - Very low birth weight (less than 3 1/2 pounds)

-Continue to next page-
44. Were any of these services offered while you were pregnant? (Check all that apply.)
- Nutrition programs
- Physical therapy
- Occupational therapy
- Genetic screening
- Mental health services
- Equipment adaptations
- None of the above
- Other: ____________________

45. Did your mobility level decrease during pregnancy?
- Yes
- No

46. How much did your mobility level change?
- A lot
- Some
- A little
- None

47. After you gave birth, were you offered any of the following services: (Check all that apply.)
- Breastfeeding education
- Postpartum physical therapy
- Postpartum occupational therapy
- Postpartum depression screening
- Postpartum depression counseling
- Support groups for mothers with disabilities
- Educational resources (e.g. websites, blogs, books)
- Family planning options (e.g. birth control pills, intrauterine devices, patch, injections)
- None of the above
- Other: ____________________

Thank you for completing this survey
Are you interested in participating in a follow-up interview to further share your insight, experiences, or thoughts regarding obstetric/gynecological related health care for women with Cerebral Palsy? If yes, please write your name and email address below and Rachel Jordan will contact you shortly.

☐ No
☐ Yes:

Name:____________________
Email:____________________