**Intracranial Hypertension Registry – Pregnancy and IH**

**I. Demographics**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| First: |  | Middle: |  | Last |  |
| Address |  |  |  | Apartment #: |  |
| City: |  | State: |  | Zip: |  |
| Home Phone: |  | Cell Phone: |  | Country: |  |
| Email Address: |  |  |  |  |  |
| Other Names Used (e.g., Maiden Name): |  |

**Race**:  Caucasian  Asian  Native American/Pacific Islander

  African American/Black  American Indian/Alaska Native  More than one Race

  Other:

**Ethnicity**:  Hispanic/Latino  Non-Hispanic/Non-Latino

**Date of Birth**: Month Day Year **Date of IH Diagnosis**: Month Year

How many times have you been pregnant?: How many live births have you had?:

How many pregnancies did you have (during or after) your diagnosis of IH?

Was your initial diagnosis of IH made during a pregnancy?  Yes  No  Not Sure

Other than IH, please list other medical problems during the time of your pregnancy(-ies) (e.g., Polycystic Ovarian Syndrome, Hypertension, Asthma):

**Instructions:**

For the following questions about your pregnancy(-ies), you will be presented with various tables. In the far left column is the number of the pregnancy. Please use line 1 for your first pregnancy (1st) and line 2 for your second pregnancy (2nd), etc. For example, in the following question regardless of the outcome of the pregnancy, line 1 would be the first pregnancy that you experienced in your lifetime and will always be placed on line 1 in all tables.

**II. General Pregnancy Information**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Pregnancy Number | Your age at time of pregnancy | Height at time of pregnancy  | Weight at the **Beginning** of your pregnancy | Amount of weight gained **during** pregnancy | Due date of pregnancy (Month, Day, Year) | Length of pregnancy in weeks (e.g., 24 weeks) | Multiple Births (e.g., twins, triplets) |
| Example | 20 | 5’ 3” | ☑ feet/inches cm | 198 | ☑ lbs kgs | 30 | ☑ lbs kgs | 09/15/2005 | 32 |  Yes☑ No |
| 1st |  |  |  feet/inches cm |  |  lbs kgs |  |  lbs kgs |  |  |  Yes No |
| 2nd |  |  |  feet/inches cm |  |  lbs kgs |  |  lbs kgs |  |  |  Yes No |
| 3rd |  |  |  feet/inches cm |  |  lbs kgs |  |  lbs kgs |  |  |  Yes No |
| 4th |  |  |  feet/inches cm |  |  lbs kgs |  |  lbs kgs |  |  |  Yes No |
| 5th |  |  |  feet/inches cm |  |  lbs kgs |  |  lbs kgs |  |  |  Yes No |
| 6th |  |  |  feet/inches cm |  |  lbs kgs |  |  lbs kgs |  |  |  Yes No |

**III. Medical and/or Surgical Interventions during pregnancy**

General anesthesia is usually performed with a mask and a breathing tube. You are completely **unconscious** through the procedure.

Local anesthesia is usually performed with an IV and you are breathing on your own (e.g., epidural or IV sedation medications). You are still **conscious or semi-conscious** through the procedure

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Pregnancy Number | Medications Taken During your pregnancy (please include all vitamins and over-the-counter drugs) | Surgeries during pregnancy | If surgery performed, what type of anesthesia was used? (General or Local?) | Number of spinal taps during your pregnancy |
| Example | Folic Acid, Prenatal Vitamins, Acetazolamide, Aspirin | Lumboperitoneal Shunt |  ☑ General  Local | 3 |
| 1st |  |  |   General  Local |  |
| 2nd |  |  |   General  Local |  |
| 3rd |  |  |   General  Local |  |
| 4th |  |  |   General  Local |  |
| 5th |  |  |   General  Local |  |
| 6th |  |  |   General  Local |  |

**IV. Diamox and Pregnancy**

Did you use Diamox during any of your pregnancies?  Yes  No (if no, go to next page)

If yes, complete the following table for the pregnancy in which you took Diamox. Remember to use the same line as earlier for this pregnancy. For example, if you took Diamox during your fourth pregnancy only, use line 4 leaving lines 1 – 3 blank.

|  |  |  |  |
| --- | --- | --- | --- |
| Pregnancy Number | During which weeks of pregnancy did you take Diamox? (e.g., 1st – 3rd and 20th – 24th) | What dosage of Diamox did you take?(1 tablet = 250 mg; 1 capsule = 500 mg) | Was your Diamox stopped once your pregnancy was discovered? |
| Example | 1- 5 and 20 - 32 | 500 mg three times a day (week 1 – 5)250 mg twice a day (week 20 -32) |  Not Sure | ☑ Yes  No |
| 1st |  |  |  Not Sure |  Yes  No |
| 2nd |  |  |  Not Sure |  Yes  No |
| 3rd |  |  |  Not Sure |  Yes  No |
| 4th |  |  |  Not Sure |  Yes  No |
| 5th |  |  |  Not Sure |  Yes  No |
| 6th |  |  |  Not Sure |  Yes  No |

**V. Pregnancy Course**

 Spontaneous Abortion means **unexpected** premature expulsion of the products of conception (a miscarriage)

 Therapeutic Abortion means termination of pregnancy which is hazardous to the life of the mother (to save your life)

 Induced Abortion means **intentional** premature termination of pregnancy by medicinal or mechanical means

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Pregnancy Number | Type of Delivery (Vaginal or C-Section) | Did you have a spontaneous abortion? | Did you have a therapeutic or medical abortion? | Did you have an induced abortion? | If you had a therapeutic or induced abortion, please explain why. |
| Example |  Vaginal☑ C-Section |  Yes ☑ No |  Yes ☑ No |  Yes ☑ No | (e.g., therapeutic abortion because of a potential stroke or uncontrolled high blood pressure) |
| 1st |  Vaginal C-Section |  Yes  No |  Yes  No |  Yes  No |  |
| 2nd |  Vaginal C-Section |  Yes  No |  Yes  No |  Yes  No |  |
| 3rd |  Vaginal C-Section |  Yes  No |  Yes  No |  Yes  No |  |
| 4th |  Vaginal C-Section |  Yes  No |  Yes  No |  Yes  No |  |
| 5th |  Vaginal C-Section |  Yes  No |  Yes  No |  Yes  No |  |
| 6th |  Vaginal C-Section |  Yes  No |  Yes  No |  Yes  No |  |

**VI. Your intracranial hypertension status AFTER pregnancy**

|  |  |  |  |
| --- | --- | --- | --- |
| Pregnancy Number | Did you continue to have IH symptoms after delivery/abortion? | Did you experience spontaneous resolution of your IH? (immediately after delivery/abortion) | Are you currently being treated for your IH? |
| Example | ☑ Yes  No |  Yes ☑ No |  Yes ☑ No |
| 1st |  Yes  No |  Yes  No |  Yes  No |
| 2nd |  Yes  No |  Yes  No |  Yes  No |
| 3rd |  Yes  No |  Yes  No |  Yes  No |
| 4th |  Yes  No |  Yes  No |  Yes  No |
| 5th |  Yes  No |  Yes  No |  Yes  No |
| 6th |  Yes  No |  Yes  No |  Yes  No |

**VII. Newborn Information**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Pregnancy Number | Child’s Full Name(First Middle Last) | Date of Delivery (Month, Day, Year) | Did your newborn have any physical abnormalities at birth? | If your newborn did have physical abnormalities at birth, please describe |
| Example | John Smith Doe | 08/05/2005 | ☑ Yes  No | Right leg longer than left leg |
| 1st |  |  |  Yes  No |  |
| 2nd |  |  |  Yes  No |  |
| 3rd |  |  |  Yes  No |  |
| 4th |  |  |  Yes  No |  |
| 5th |  |  |  Yes  No |  |
| 6th |  |  |  Yes  No |  |

**VIII. Child(ren)’s Present Status**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Pregnancy Number | Is the child living? | What is the current age of the child? | Does the child have any physical medical problems? (e.g., Asthma, Leukemia, etc…) | Does the child have any non-physical problems? (e.g., ADHD, Dyslexia, Bipolar Disorder, etc…) |
| Example | ☑ Yes  No | 2 ½ | Asthma | Autism |
| 1st |  Yes  No |  |  |  |
| 2nd |  Yes  No |  |  |  |
| 3rd |  Yes  No |  |  |  |
| 4th |  Yes  No |  |  |  |
| 5th |  Yes  No |  |  |  |
| 6th |  Yes  No |  |  |  |

**IX. Physicians**

**Please list the doctor that diagnosed your intracranial hypertension. If you are unable to remember your physician’s names, please list the institution or hospital that you were seen at (i.e., Johns Hopkins Medical Center).**

Name: Specialty:

Hospital/University:

City: State:

Date seen (month & year):

**Please list the doctor that you saw who managed your intracranial hypertension during your pregnancy(-ies).**

  Same as Above

Pregnancy Number

(please circle):

1 2 3

4 5 6

Pregnancy Number

(please circle):

1 2 3

4 5 6

Name: Specialty:

Hospital/University:

City: State:

Date seen (month & year):

Name: Specialty:

Hospital/University:

City: State:

Date seen (month & year):

**Please list the doctor that you saw who currently manages your intracranial hypertension.**

Name:

* Neurologist
* Ophthalmologist
* Neuro-Ophthamologist

Hospital/University:

City: State:

Date seen (month & year):

Name:

* Neurologist
* Ophthalmologist
* Neuro-Ophthamologist

Hospital/University:

City: State:

Date seen (month & year):

**Please list your obstetrician and any other physician who provided care during your pregnancy(-ies)?**

Pregnancy Number

(please circle):

1 2 3

4 5 6

Pregnancy Number

(please circle):

1 2 3

4 5 6

Name: Specialty:

Hospital/University:

City: State:

Date seen (month & year):

Name: Specialty:

Hospital/University:

City: State:

Date seen (month & year):

**Please list your child(ren)’s pediatrician(s) and/or other physicians who provides care for your child(ren).**

Name: Specialty:

Pregnancy Number

(please circle):

1 2 3

4 5 6

Hospital/University:

City: State:

Date seen (month & year):

Child(ren)’s Name(s):

Name: Specialty:

Pregnancy Number

(please circle):

1 2 3

4 5 6

Hospital/University:

City: State:

Date seen (month & year):

Child(ren)’s Name(s):

***Thank you for completing this questionnaire***

***and***

***contributing to research on Intracranial Hypertension.***