

Note: *When we receive this survey, this information page will be separated and removed from the rest of the survey to protect the confidentiality of your responses.*

NAME _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

" I choose not to complete the survey at this time.

GENERAL INFORMATION

Date of birth of your child with Down syndrome _____

Sex of your child with Down syndrome (*circle one*) MALE FEMALE

How old were you when you had your child with Down syndrome? _____

POSTNATAL MEDICAL SUPPORT

The following statements are about the support that you received immediately after the birth of your child with Down syndrome. You will be asked questions about what your physician discussed with you and how you responded to such information.

(Please circle the number which most accurately reflects your opinion about the following statements with 7 being “strongly agree,” 1 being “strongly disagree,” and 4 being “neutral.”)

	Strongly disagree		Neutral			Strongly agree	
	1	2	3	4	5	6	7
The birth of my child with Down syndrome was a positive experience.	1	2	3	4	5	6	7
My physician told me about the positive aspects of children with Down syndrome.	1	2	3	4	5	6	7
My physician told me about the negative aspects of children with Down syndrome.	1	2	3	4	5	6	7
My physician emphasized the positive aspects of Down syndrome.	1	2	3	4	5	6	7
My physician emphasized the negative aspects of Down syndrome.	1	2	3	4	5	6	7
My physician provided me with enough phone numbers of parents who have a child with Down syndrome.	1	2	3	4	5	6	7
My physician provided me with enough up-to-date printed material on Down syndrome.	1	2	3	4	5	6	7
The printed materials that I received from my physician emphasized the positive aspects of Down syndrome.	1	2	3	4	5	6	7
The printed materials that I received from my physician emphasized the negative aspects of Down syndrome.	1	2	3	4	5	6	7
The printed materials that I received from my physician provided an equal mix about the positive and negative aspects of Down syndrome.	1	2	3	4	5	6	7
The printed materials were helpful in understanding Down syndrome.	1	2	3	4	5	6	7
The printed materials were easy to read and understand.	1	2	3	4	5	6	7

	Strongly disagree		Neutral			Strongly agree	
My physician pitied me.	1	2	3	4	5	6	7
When I learned that my child had Down syndrome, I was frightened.	1	2	3	4	5	6	7
When I learned that my child had Down syndrome, I was anxious.	1	2	3	4	5	6	7
When I learned that my child had Down syndrome, I experienced suicidal thoughts.	1	2	3	4	5	6	7
When I learned that my child had Down syndrome, I felt positive.	1	2	3	4	5	6	7
When I learned that my child had Down syndrome, I had no prior knowledge about this genetic condition.	1	2	3	4	5	6	7

PRENATAL TESTING

The following statements are about the support that you received during the period between the diagnosis of Down syndrome and the birth of your child. You will be asked questions about what your physicians discussed with you and how you responded to such information.

[If you did not receive prenatal testing, skip to page 9.]

[If you received prenatal testing, continue on this page and the next.]

(Please circle the number which most accurately reflects your opinion about the following statements with 7 being “strongly agree,” 1 being “strongly disagree,” and 4 being “neutral.”)

	Strongly disagree		Neutral			Strongly agree	
My physician was supportive of my decision to continue my pregnancy.	1	2	3	4	5	6	7
My physician tried to change my decision about continuing my pregnancy.	1	2	3	4	5	6	7
The prenatal medical support that I received following my decision to continue my pregnancy was exceptionally good.	1	2	3	4	5	6	7
After I decided to continue my pregnancy, it was a struggle to find adequate prenatal care.	1	2	3	4	5	6	7
After I decided to continue my pregnancy, my physician began giving me parenting tips on how best to raise a child with Down syndrome	1	2	3	4	5	6	7

PRINTED MATERIALS ON DOWN SYNDROME

You will be asked questions about any books, pamphlets, magazines, or handouts on Down syndrome that you received from your physician before the birth of your child with Down syndrome.

[NOTE: If you did not receive any printed materials from your physician and/or genetic counselor while you were pregnant, please skip to the question #2 at the bottom of this page.]

	Strongly disagree		Neutral			Strongly agree	
The printed materials that I received provided an equal mix about the positive and negative aspects of Down syndrome.	1	2	3	4	5	6	7
The printed materials that I received emphasized the negative aspects of Down syndrome.	1	2	3	4	5	6	7
The printed materials that I received emphasized the positive aspects of Down syndrome.	1	2	3	4	5	6	7
The printed materials were helpful in understanding Down syndrome.	1	2	3	4	5	6	7
The printed materials encouraged me to continue my pregnancy.	1	2	3	4	5	6	7
The printed materials encouraged me to terminate my pregnancy	1	2	3	4	5	6	7
I liked the printed materials that I received.	1	2	3	4	5	6	7
The printed materials were easy to read and understand.	1	2	3	4	5	6	7

1. What printed materials were you given on Down syndrome?

2. What types of printed materials do you wish you would have received—but didn't—after receiving a triple screen or amniocentesis result of Down syndrome?

<<continue on to the next page>>

TRIPLE SCREEN TEST (or AFP TEST)

You will be asked questions about what your physician discussed with you concerning the triple screen test and your reactions to such information. [A “triple screen” is a test commonly performed during the 16th to 18th weeks of pregnancy to look for elevated concentrations of biochemical markers for Down syndrome (namely, alpha-fetoprotein, unconjugated estriol, and unconjugated human chorionic gonadotrophin). It includes the “AFP” test.]

Did you have a “triple screen” and/or AFP test that indicated an enhanced risk of having a child with Down syndrome? YES NO

If yes, how many weeks pregnant were you at the time? _____

[If you answer “yes,” please continue on this page and the next.]

[If you answer “no,” please skip to the next page.]

Please circle the number which most accurately reflects your opinion about the following statements with 7 being “strongly agree,” 1 being “strongly disagree,” and 4 being “neutral.”

	Strongly disagree		Neutral			Strongly agree	
	1	2	3	4	5	6	7
Before the “triple screen” procedure, I already had a good idea about what Down syndrome was.	1	2	3	4	5	6	7
Before receiving test results from the “triple screen,” my physician explained to me what Down syndrome was.	1	2	3	4	5	6	7
After receiving test results, my physician explained to me what Down syndrome was.	1	2	3	4	5	6	7
After receiving the results, I felt encouraged by my physician to terminate my pregnancy.	1	2	3	4	5	6	7
After receiving the results, I felt encouraged by my physician to continue my pregnancy.	1	2	3	4	5	6	7
After receiving test results, I felt scared.	1	2	3	4	5	6	7
After receiving test results, I felt anxious.	1	2	3	4	5	6	7
After receiving test results, I experienced suicidal thoughts.	1	2	3	4	5	6	7
After receiving test results, I felt positive.	1	2	3	4	5	6	7
After receiving test results, I feel my physician gave me enough up-to-date printed material on Down syndrome.	1	2	3	4	5	6	7

AMNIOCENTESIS TEST

You will be asked questions about how your physicians explained and discussed the results of amniocentesis, in addition to your reaction to such information. [Amniocentesis is a test performed during the second and/or third trimester of pregnancy which analyzes the fetal cells in the amniotic fluid of a pregnant woman. It offers a definitive diagnosis of Down syndrome in a fetus.]

Did you have an amniocentesis to detect Down syndrome? YES NO

If yes, how many weeks pregnant were you at the time? _____

[If you answered “yes,” continue on this page and the next.]

[If you answered “no,” please skip to page 8.]

Please circle the number which most accurately reflects your opinion about the following statements with 7 being “strongly agree,” 1 being “strongly disagree,” and 4 being “neutral.”

	Strongly disagree		Neutral			Strongly agree	
	1	2	3	4	5	6	7
I wanted to have an amniocentesis done.	1	2	3	4	5	6	7
I felt encouraged by my physician to have an amniocentesis.	1	2	3	4	5	6	7
I felt pressured by my physician to have an amniocentesis.	1	2	3	4	5	6	7
My physician explained the results to me in a manner that I could understand.	1	2	3	4	5	6	7
After receiving the results, my physician encouraged me to terminate my pregnancy.	1	2	3	4	5	6	7
After receiving the results, my physician encouraged me to continue my pregnancy.	1	2	3	4	5	6	7
After receiving the results, I felt scared.	1	2	3	4	5	6	7
After receiving the results, I felt anxious.	1	2	3	4	5	6	7
After receiving the results, I experienced suicidal thoughts.	1	2	3	4	5	6	7
After receiving the results, I felt positive.	1	2	3	4	5	6	7
Before the amniocentesis, I already had a good idea about what Down syndrome was.	1	2	3	4	5	6	7
After receiving test results, my physician told me about the positive aspects of children with Down syndrome.	1	2	3	4	5	6	7
After receiving test results, my physician told me about the negative aspects of children with Down syndrome.	1	2	3	4	5	6	7
After receiving test results, my physician gave me his/her opinion about what he/she would do in my situation.	1	2	3	4	5	6	7
I am glad that my physician gave me his/her opinion about what he/she would do in my situation.	1	2	3	4	5	6	7

	Strongly disagree		Neutral			Strongly agree	
After receiving test results, my physician provided me with enough phone numbers of parents who have a child with Down syndrome.	1	2	3	4	5	6	7
After receiving test results, my physician gave me enough up-to-date printed material on Down syndrome.	1	2	3	4	5	6	7
My physician emphasized the negative aspects about Down syndrome.	1	2	3	4	5	6	7
My physician emphasized the positive aspects about Down syndrome.	1	2	3	4	5	6	7
My physician pitied me.	1	2	3	4	5	6	7
After receiving my amniocentesis result, I felt rushed or pressured into making a decision about the continuation of my pregnancy.	1	2	3	4	5	6	7

- c. I received the results of my amniocentesis in person. YES NO
- d. If you were married or with your partner at the time, did your physician give the results in the presence of both persons? YES NO
- e. I had an amniocentesis because of the results from my “triple screen.” YES NO
- f. I had an amniocentesis because of the results from ultrasound findings. YES NO
- g. I had an amniocentesis because of my age. YES NO
- h. Other reasons why you had an amniocentesis? _____
- i. How could the amniocentesis process have been better?

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DECIDING TO CONTINUE YOUR PREGNANCY

(Please circle the number which most accurately reflects your opinion about the following statements with 7 being “strongly agree,” 1 being “strongly disagree,” and 4 being “neutral.”)

The following factors played an important role in my decision to continue my pregnancy . . .

	Strongly disagree		Neutral			Strongly agree	
my physician’s opinion	1	2	3	4	5	6	7
my parents’ opinion	1	2	3	4	5	6	7
my husband’s/partner’s opinion	1	2	3	4	5	6	7
my religion	1	2	3	4	5	6	7
my “inner voice”	1	2	3	4	5	6	7
the printed material given to me by my physician and/or genetic counselor	1	2	3	4	5	6	7
the verbal information given to me by my physician	1	2	3	4	5	6	7
the verbal information given to me by my genetic counselor	1	2	3	4	5	6	7
Material that I found on my own	1	2	3	4	5	6	7
my friends’ opinion	1	2	3	4	5	6	7
talking to another parent who had a child with Down syndrome	1	2	3	4	5	6	7
meeting a person with Down syndrome	1	2	3	4	5	6	7
seeing children with Down syndrome on TV, in a movie, or in the media	1	2	3	4	5	6	7
This was the only child that I was going to conceive.	1	2	3	4	5	6	7
I was not offered or allowed an abortion.	1	2	3	4	5	6	7
positive images and stories about persons with Down syndrome in printed materials	1	2	3	4	5	6	7
the positive aspects of Down syndrome that were stressed by my physician	1	2	3	4	5	6	7
I am related to a person with Down syndrome	1	2	3	4	5	6	7
the genetic counselor’s opinion	1	2	3	4	5	6	7
Other _____	1	2	3	4	5	6	7

You are not required to answer any of these questions, but it would be appreciated.

YOUR DATE OF BIRTH _____ TODAY'S DATE _____

YOUR SEX (*circle one*): Male Female

Your ethnicity

" African American or Black

" Hispanic or Latino

" White

" Asian

" American Indian or Alaska Native

" Native Hawaiian

" Other _____

What is the highest level of your education?

" didn't graduate from 8th grade

" graduated from 8th grade

" graduated from high school

" graduated from college

" received Master's degree

" received doctorate degree

What is your religious affiliation?

What is the total combined income of your household?

In what state did you receive medical care for your pregnancy?

State _____

How many other pregnancies have you had?

<<continue to next page>>

Please use this space to describe or list anything else about your prenatal care, pregnancy, and/or postnatal care that you deem important, either positive or negative. Are there any incidents or stories that you would like to share?