

**Part I: These questions ask about finding a genetic result, which is the change(s) in your child's genes that was returned to you.**

How were you told about the genetic result?

- In person by a genetic counselor or doctor who specializes in genetics
- In person by a doctor, nurse, or nurse practitioner who does not specialize in genetics
- Over the phone by a genetic counselor or doctor who specializes in genetics
- Over the phone by a doctor, nurse, or nurse practitioner does not specialize in genetics
- Other

Please explain how you were told about the genetic result:

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When were you told about the genetic result?

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Do you think the genetic result explains your child's health problems?

- Yes, fully
- Yes, partially
- Unsure
- No

Does your child's doctor think the genetic result explains your child's health problems?

- Yes, fully
- Yes, partially
- Unsure
- No

How important is having a genetic result for your child?

- Not at all important
- Slightly important
- Moderately important
- Very important
- Extremely important

We are interested in your feelings about the following statements:

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Having a genetic result has helped me understand my child's current health problems

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

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Having a genetic result has helped me worry less about my child's health problems

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

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Having a genetic result has not helped me prepare for my child's future

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

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Having a genetic result has caused me to feel responsible for my child's health problems

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

---

Having a genetic result has helped me feel less alone

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

---

Having a genetic result has helped me find better treatments for my child's health problems

- strongly disagree
- disagree
- neutral
- agree
- strongly agree

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My child has been referred to additional specialists based on their genetic result

- Yes
- No

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How many?

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My child has been able to stop seeing specialist(s) based on their genetic result

- Yes
- No

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How many?

\_\_\_\_\_

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My child has been prescribed new medication(s) based on their genetic result

- Yes  
 No

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How many?

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My child has been able to stop taking certain medication(s) based on their genetic result

- Yes  
 No

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How many?

\_\_\_\_\_

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My child has become eligible for an additional research study based on their genetic result

- Yes  
 No  
 Unsure

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Having a genetic result has improved/opened access to supportive services (e.g. occupational therapy, speech therapy, home health services, etc.)

- strongly disagree  
 disagree  
 neutral  
 agree  
 strongly agree  
 not applicable

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Having a genetic result has improved/opened access to school support

- strongly disagree  
 disagree  
 neutral  
 agree  
 strongly agree  
 not applicable

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Having a genetic result has allowed me to connect with a new gene- or disease-specific group

- strongly disagree  
 disagree  
 neutral  
 agree  
 strongly agree  
 not applicable

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Having a genetic result has not helped me connect with other families

- strongly disagree
- disagree
- neutral
- agree
- strongly agree
- not applicable

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Having a genetic result has made an overall positive impact on relationships in my family

- strongly disagree
- disagree
- neutral
- agree
- strongly agree
- not applicable

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Having a genetic result has helped me decide whether or not to have more children

- strongly disagree
- disagree
- neutral
- agree
- strongly agree
- not applicable (I am not planning on having more children)

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Having a genetic result has helped me plan for my/my partner's future pregnancy

- strongly disagree
- disagree
- neutral
- agree
- strongly agree
- not applicable (I am not planning on having more children)

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Has the genetic result had any other impact on you, your child, or your family? Please tell us below:

**Part II: The questions in this scale ask you about your feelings and thoughts during THE LAST MONTH. In each case, please indicate your response by selecting the option representing HOW OFTEN you felt or thought a certain way.**

In the last month, how often have you been upset because of something that happened unexpectedly?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

In the last month, how often have you felt that you were unable to control the important things in your life?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

In the last month, how often have you felt nervous and "stressed"?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

In the last month, how often have you felt confident about your ability to handle your personal problems?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

In the last month, how often have you felt that things were going your way?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

In the last month, how often have you found that you could not cope with all the things that you had to do?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

In the last month, how often have you been able to control irritations in your life?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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In the last month, how often have you felt that you were on top of things?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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In the last month, how often have you been angered because of things that were outside your control?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

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In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

- Never
- Almost never
- Sometimes
- Fairly often
- Very often

**Part III: The final questions ask for some basic information about you that may have changed since the last time you completed the survey.**

What is your current marital status?

- Married
- Widowed
- Divorced
- Separated
- Never married

Are you currently living with a spouse, partner, or boyfriend/girlfriend?

- Yes
- No

What is the highest grade or year of school you completed?

- Never attended school
- Grade school (grades 1 to 8)
- Some high school (grades 9 to 12)
- High school graduate or GED
- Post high school training other than college (vocational, technical, or other types of training)
- Some college
- Bachelor's degree or equivalent
- Master's degree (MS, MBA, MFA, etc.)
- Professional degree (MD, DDS, DVM, etc.)
- Doctorate (PhD, EdD, etc.)

What is your current work situation? (check all that apply)

- Working
- Homemaker
- Student
- Sick leave or maternity leave
- Laid off, looking for work, or otherwise unemployed
- Retired
- Disabled, permanently or temporarily
- Other

What is your household's total combined income during the past 12 months? (This includes money from pensions, social security payments, jobs, net income from business, farm or rent, dividends, interest and any other income received by family members who are 15 years of age or older.)

- Less than \$15,000
- \$15,000 to \$19,999
- \$20,000 to \$24,999
- \$25,000 to \$39,999
- \$40,000 to \$89,999
- \$90,000 to \$149,999
- \$150,000 to \$199,999
- \$200,000 or above
- Prefer not to answer

Including yourself, how many people currently live in your household?

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Do you have health insurance or a health coverage plan? (Check all that apply)

- Yes, through my employer or someone else's employer
- Yes, through government sponsored programs such as Medicaid, Medicare, etc.
- No, I don't have any coverage
- Don't know