

Part I: These questions ask about finding a genetic diagnosis, which is a change in your child's genes that causes health problems and could explain why your child has a rare disease.

How important is finding a genetic diagnosis 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:

Finding a genetic diagnosis will help me understand my child's current health problems

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

Finding a genetic diagnosis will cause me to feel responsible for my child's health problems

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

Finding a genetic diagnosis will help me worry less about my child's health problems

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

Finding a genetic diagnosis will help me prepare for my child's future

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

Finding a genetic diagnosis will help me find better treatments for my child's health problems

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

Finding a genetic diagnosis will help me connect with other families

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

Finding a genetic diagnosis will help me feel less alone

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

Finding a genetic diagnosis will help 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)

Finding a genetic diagnosis will help 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)

Part II: The next questions ask about how much money and time you spend caring for your child.

Have your child's health conditions caused financial problems for your family?

- Yes
- No
- Don't know

How many hours per week do you or other family members spend arranging or coordinating your child's medical care? This means making appointments, making sure that care providers are exchanging information, and following up on your child's healthcare needs.

It is fine to provide an average number of hours per week based on several weeks. Please give your best estimate.

- Less than 1 hour
- 1-3 hours
- 3-5 hours
- 5-7 hours
- 7-9 hours
- 10 or more hours
- Don't know

Have you or other family members stopped working because of your child's health conditions?

- Yes
- No
- Don't know

Besides any family members who stopped working, have you or other family members cut down on the hours you work because of your child's health conditions?

- Yes
- No
- Don't know

Have you or other family members avoided changing jobs because of concerns about maintaining health insurance for your child?

- Yes
- No
- Don't know

Part III: 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

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

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

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

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 IV: The final questions ask for some basic information about you.

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?

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