

Attachment 8

CMV Parent Survey for All Parent Groups

Thank you for taking time from your busy schedule to complete this survey. This research is being sponsored by the Centers for Disease Control and Prevention. The information you provide today will be extremely useful to other parents and to professionals working on CMV. Please note that no identifying information will be collected in this survey today. It is completely anonymous. If there are any questions you do not want to answer or feel are too sensitive you are free to not reply or skip that question. In fact, you are free to discontinue the survey at any time. This survey should take you between 5-10 minutes to complete.

Kirby Marketing Solutions is working with Dr. Gail Demmler-Harrison's CMV clinic on a project to help us better understand the kinds of positive and negative mental, emotional, financial, and family issues that parents may experience when their child is first tested for CMV or diagnosed with CMV, and during the following critical years as follow-up tests are completed. Because we are trying to understand the ways that CMV testing and follow-up may have impacted you or your family, it is very important to try to remember your feelings at that time

If you have any other questions, please call _____ at the CMV clinic and ask for _____, who can answer your questions.

Thank you again for your time.

Instructions: Try to base your answers on the time period when your child was first diagnosed with congenital CMV infection and the following few years. The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided for questions 1-28.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

1. My child is so active that it exhausts me.
2. Compared to most, my child has more difficulty concentrating and paying attention.
3. My child rarely does things for me that make me feel good.
4. My child smiles at me much less than I expected.
5. My child seems to cry or fuss more often than most children.
6. My child is not able to do as much as I expected.
7. When my child came home from the hospital, I had doubtful feelings about my ability to handle being a parent.
8. Being a parent is harder than I thought it would be.
9. I feel capable and on top of things when I am caring for my child.

Public reporting burden of this collection of information is estimated to average 10 minutes, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0920-XXXX)

10. Leaving my child with a babysitter is usually a problem.
11. There are some things my child does that really bother me a lot.
12. My child has had more health problems than I expected.
13. As my child has grown older and become more independent, I find myself more worried that my child will get hurt or into trouble.
14. My child turned out to be more of a problem than I had expected.
15. I have had many more problems raising children than I expected.
16. I enjoy being a parent.
17. Since I brought my last child home from the hospital, I find that I am not able to take care of this child as well as I thought I could. I need help.
18. Most of my life is spent doing things for my child.
19. I find myself giving up more of my life to meet my children's needs than I ever expected.
20. I feel trapped by my responsibilities as a parent.
21. Since having a child, I feel that I am almost never able to do things that I like to do.
22. I often feel guilty about the way I feel toward my child.
23. I felt sadder and more depressed than I expected after leaving the hospital with my baby.
24. After my child had been home from the hospital for about a month, I noticed that I was feeling more sad and depressed than I had expected.
25. Since having my child, my spouse (male/female friend) has not given me as much help and support as expected.
26. Having a child has caused more problems than I expected in my relationship with my spouse (male/female friend).
27. Having a child seems to have increased the number of problems we have with in-laws and relatives.
28. When I run into a problem taking care of my children, I have a lot of people to whom I can talk to get help or advice.

FOR STATEMENT 29, CHOOSE FROM CHOICES 1 to 5 BELOW:

29. When I think about myself as a parent I believe:
1. I can handle anything that happens
 2. I can handle most things pretty well
 3. Sometimes I have my doubts, but find that I handle most things without any problems.
 4. I have some doubts about being able to handle things.
 5. I don't think I handle things very well at all.

STATEMENTS 30-36, CHOOSE FROM CHOICES Y for "Yes" and N for "No."

During the time your child was initially diagnosed with congenital CMV infection and the following few years of follow-up testing, did any of the following events occurred in your immediate family?

30. Separation
31. Divorce
32. Pregnancy
33. Went deeply into debt
34. Trouble with superiors at work
35. Trouble with teachers at school
36. Legal problems

That concludes our survey. Thank you again for your help.