Form Approved
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Attachment 3

Parent Focus Group Guide
(Parents of children born with CMV who were asymptomatic and did not develop sequelae)

Consent

Good afternoon, my name is ______________. I want to thank you in advance for taking time from your busy schedule to participate in this focus group. 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 congenital CMV. When one of the CMV staff members called and asked you to participate today you were told that this focus group is entirely voluntary, that no LAST names will be used today or in our reporting of the data, and that if there are any questions you do not want to answer or feel are too sensitive you are free to not reply or to write down your comments and hand them to me after the session if you'd prefer. In fact, you are free to leave the focus group session at any time. We will be recording today's session, so please try to speak one at a time. If each of you could signify by saying your FIRST NAME ONLY and YES you understand how your privacy is being protected we can proceed. [*The moderator will go around the table and ask each participant to state their agreement with the informed consent*]. I'll stop for a minute to see if there are any questions- anyone?

Purpose

As I said my name is _________ and I am working with Dr. Gail Demmler-Harrison and her CMV team on a project to help us better understand the kinds of positive and negative mental, emotional, financial, and family issues that parents experience when their child is first tested for congenital CMV and in the following critical years of development as follow-up tests may be completed. One of the best ways for us to do that is to talk directly to people like you who know a lot about those experiences. I will be asking you to share your thoughts, feelings, and opinions about these experiences. Please remember that there are no right or wrong answers—we just want to know about your own thoughts, whatever they may be. I want to encourage you all to participate in an open discussion. From time to time I may move the discussion so we can cover all of our topics tonight. Let me stop and ask if there are any questions so far.

The last important thing to know is that each of you in this group share the experience of having a child test positive for congenital CMV. [*Moderator to note this group is Parents whose child was asymptomatic, C-CMV positive, but did not develop sequelae*]

Procedures

- Session should last about an hour to an hour and a half
- This is a group discussion, so you don't have to wait to be called on
- Secure – when we report about these conversations later, not even your FIRST name will be used in the report.
- The restrooms are ____. Feel free to get up at any time during our discussion.
- Please help yourself to the refreshments

Public reporting burden of this collection of information is estimated to average 1.5 hours, 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)

Any other questions before we start? Okay, let's get started.

Warm Up and Opening Question (5 minutes)

1. First, I'd like to go around the table and have each of you tell me your FIRST name only and one of your memories from the first 5 years of life of your child who was born infected with CMV. [*Moderator will encourage any kind of memory sharing they prefer*].

Negative Psychosocial Impacts of CMV Test and Follow-up Testing *(Note: moderator will rotate the positive and negative impacts sections among the focus group sessions to minimize any order bias].*

2. As you all know raising a child can have its ups and downs. But we are particularly interested in your memory of experiences you had when your child was first diagnosed positive for congenital CMV. So take a minute and think back now to that time, when your child was an infant and you received this testing news. Tell me about your first reactions?

3. After the positive CMV test results were given to you, what would you say were the first few things you wanted to know? Was anyone able to answer those questions for you?

4. In those first few days tell me how you felt about yourself in regards to the positive test? [Probe for feeling alone, feeling responsible, being scared, feeling overwhelmed, no major concerns, not a problem].

5. In the first few days that followed the positive CMV test results, tell me about any kinds of family or marital stress you experienced. [Moderator to probe for spousal issues like blaming, concerns about how my other children and how they would cope, worries about what my family would think/react].

6. Can you tell me what you thought about in terms of financial issues related to the positive test results? Did you worry about anything, what kinds of things? [Probe for concerns about enough money to have necessary follow-up tests done, concerns about health insurance coverage, worries about how I can care for this child and my other children].

7. Now let's talk a little about the years following the initial test results. All of you participated in the follow-up clinic for some period of time. After the first few months, what kinds of new concerns or stressful issues surfaced? [Probe for stressors specific to self, marriage/spouse, and parenting skills/efficacy].

8. After the first few months, what kinds of new concerns or stressful issues surfaced related to your family, friends, and other social networks (e.g., church)?

9. Now thinking about the medical professionals you met with over those first few years, were there any additional stressors from those meetings? What kinds of things frustrated you? What could have been explained better? Thinking about new parents today, how would you explain some of the things that frustrated you?

10. Now thinking about those extra doctor visits and follow-up tests that your child went through, what kinds of stress or negative impacts did those activities or tests have on you and your family? [Probe for transportation hassles of getting to appointments, concerns about time off of work to get to appointments, costs of travel, difficulty with child care for other children].

11. Now let's talk about your interactions with your child. Thinking back over those first few years, how would you characterize your relationship with your child? [Probe for stressors related to child behaviors, lack of affection, too much affection/attention, over-protectiveness].

12. If you have other children, did you feel that your relationship with your CMV+ child was different in some ways due to the CMV? How so?

13. As your child got older, what kinds of concerns did they have about the doctor visits and follow-up tests? What could have been done or said to you to improve that experience for you and for your child?

<u>Positive Psychosocial Impacts</u> *(Note: moderator will rotate the positive and negative impacts sections among the focus group sessions to minimize any order bias].*

Now let's switch gears and talk about some of the positive aspects of having the CMV test done and the knowledge that came with that.

14. Thinking back to initial diagnosis of congenital CMV infection in your newborn child, what would you say was the most positive aspect of getting those results?

15. Now thinking about the following few years and the doctor visits and follow up tests that you and your child went through, what would you say are the best things about having done those visits and tests? [Probe for the kinds of concerns that the follow-up testing minimized].
    a. What would you say were the worst things about having done those visits and tests?

16. All in all, tell me about your thinking about the value of CMV testing and follow-up testing. Were the tests worth the troubles, stress, and issues that the testing caused for you as a parent?
    a. What about how worthwhile it was for your child?

Communication about CMV Testing

17. What are the three most important things you would want to say to other parents about having a child born with CMV infection?
    a. Does what you need to tell parents differ as the child gets older? How so?
    b. Where do you tell them to get more information if they need it?
    c. Are there good Internet resources you would send them to? Which ones?

18. Who do you think does a better job helping with the information needs of parents of newly diagnosed children, other parents, doctors, nurses, others? What is that they do better?

19. Based on your experience, do you think newborn CMV testing should be offered to all new parents? If you think so, what concerns would you have about that? Also, should the testing be mandatory or should it require parental permission? Why or why not?

20. What are the three most important things you would want to say to other parents about having a positive CMV test result?
    a. Does what you need to tell parents differ as the child gets older? How so?
    b. Where do you tell them to get more information if they need it?
    c. Are there good Internet resources you would send them to? Which ones?

Closing Thoughts

21. Before we finish up today, I'd like to ask if there are any other topics or issues, positive or negative, that you would like to mention?

Thank you all so much. Your thoughts and insights today have been very helpful to this project. We will be conducting group meetings with other parents and interviewing some parents as well. After that we will be conducting a mail survey to collect more detailed information from all of you. If you do not want to be contacted about that survey, please let one of the CMV staff people know that. One of them will also make sure you have parking tokens and are signed up to receive the $25 incentive as a token of appreciation for your interest. Thank you again and drive safely going home.