

## Attachment C6: Focus Group Confirmation Letter

[Name]  
[Address]  
[City] [State]

Dear [Ms./Mr.] [Name]:

Thank you for agreeing to participate in a group discussion about coordinating care for individuals with spina bifida. Your thoughts and experiences as a caregiver of a child with spina bifida are crucial to this study.

- You are scheduled to participate on [DATE, TIME].
- The discussion group will take place at [FOCUS GROUP ADDRESS] (Please see enclosed map).
- Light refreshments will be provided.
- As a token of appreciation, we will give you \$40 following the discussion.

We will call you a few days before the group discussion to answer any questions you may have and to confirm your participation. Your participation is extremely important to CDC. If for any reason you will be unable to participate as scheduled, please contact me at 1-800-444-5234, ext. 109 so that we may reschedule you and/or schedule an alternate.

Sincerely,

Darcy Holtgrave  
Battelle Project Coordinator

## **Attachment C8: Focus Group Consent Form**

Flesch-Kincaid Grade Level: 7.1

### **The Spina Bifida Care Coordination Study**

#### **Consent to Participate in a Discussion (Focus) Group**

##### **Why are we doing this study?**

The Spina Bifida Association (SBA) and the Centers for Disease Control and Prevention (CDC) want to find out how care coordination is being done in spina bifida clinics. They also want to learn how families and clinic staff feel about the service. By “care coordination” we mean some kind of planning and organization for the care that a person with spina bifida receives. CDC contracted with a company named Battelle to do a research study about this. Battelle will lead groups with family members of people with spina bifida.

##### **What will I be doing if I am in this study?**

You have been invited to take part in a group with up to 9 other people. They are all family members of a person with spina bifida. We will talk about how care coordination is done in the spina bifida clinic your family member goes to. We will ask you questions about the services that the patient receives at this clinic. We will ask if a plan of care has been set up and what it is like. We will also ask if anyone helps you to coordinate this care, who that is, and how they do it.

The meeting will last about 2 hours. We will record the meeting so that we have a tape of what people said. We will give you \$40 to thank you for being in the group. We will have refreshments during the meeting.

##### **Are there any risks to being in this study?**

You may be uncomfortable talking in the group about the health care your family member gets.

##### **What are the benefits to being in this study?**

You will not benefit directly from being in the study. However, CDC may use what we learn from these groups to make recommendations about how spina bifida clinics could improve or increase care coordination services.

##### **What about my privacy?**

All personal information that we get about you during our group meeting will be kept private and your identity will not be shared with anyone. We will not share your name or other information about you, with other people. No one who was in the study will be named in any reports or written records. We will keep study

records without names. We will erase all tapes or disks when the data collection is over.

**Do I have to be in this study?**

You do not have to be in this study. If you do not want to be in this study, it will not affect you in any way. It will not affect the care that your family member gets from the spina bifida clinic. The clinic staff will not act any differently to you or your family member. If you would like to take part in the group but do not like some of the questions, you do not have to answer them. You may leave the group at any time.

**Who do I speak to if I have questions about this study?**

If you have any questions about this study, you may call the Battelle Project Coordinator, Darcy Holtgrave at 1-800-444-5234 ext. 109 or 314-993-5234 ext 109. You may also call any of the project team members if you have any questions or concerns. Information about how to get in touch with project team members is on the next page.

**Project Team Contacts**

You may contact any of the following people if you have questions, concerns, or complaints about the research study.

Battelle Project Director:

Jennifer Brustrom  
Battelle Centers for Public Health Research and Evaluation  
2971 Flowers Road South, Suite 233  
Atlanta, GA 30341  
(770) 451-0882 x20  
(770) 451-6612 (fax)  
brustromj@battelle.org

Centers for Disease Control and Prevention (CDC) Project Coordinator:

Judy Thibadeau  
Centers for Disease Control and Prevention  
Division of Human Development and Disability, MS-E-88  
1600 Clifton Road, Atlanta, GA 30333  
(404) 498-3559  
(404) 498-3060 (fax)  
jthibadeau@cdc.gov

If you have any questions or concerns about your rights as a research participant, please call:

Battelle Institutional Review Board Chair:

Battelle/CPHRE IRB Chair  
100 Capitola Drive

Suite 301  
Durham, NC 27713-4411  
(877) 810-9530, ext. 500 (toll-free)  
(919) 544-0830 (fax)