

<b>Section A: KEY IDENTIFYING INFORMATION</b>
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A1. Study Identification Number \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_ - \_\_\_\_\_

A2. Acrostic Identifier \_\_\_\_\_

A3. Study visit  
 Study Visit 6 (age 3 year).....6  
 Study Visit 7 (age 4 year).....7  
 Study Visit 8 (age 5 year).....8  
 Study Visit 9 (age 6 years).....9

A4. Patient date of birth  
 \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

M M / D D / Y Y Y Y

A5. Patient gender  
 MALE ..... 1 FEMALE.....2

A6. Was the form completed without assistance from the study coordinator or other health care provider?  
 YES.....1 NO.....2 **(A6b)**

a. Who completed the form? (without assistance)  
 Mother .....1 **(A7)**  
 Father .....2 **(A7)**  
 Other primary caregiver.....3

1. If other primary caregiver, specify: \_\_\_\_\_ **(A7)**

b. Who completed the form? (with assistance)  
 Mother .....1 **(A7)**  
 Father .....2 **(A7)**  
 Other primary caregiver.....3

1. If other primary caregiver, specify: \_\_\_\_\_

A7. Are there siblings living in the home? YES.....1 NO.....2 **(A8)**

a. Are one or more siblings 4 years of age or older? YES.....1 NO.....2

A8. Date of instrument completion by parent or caregiver  
 \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

M M / D D / Y Y Y Y

A9. Date of form completion  
 \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

M M / D D / Y Y Y Y

A10 Name of person completing form  
 \_\_\_\_\_  
 PRINT FULL NAME INITIALS

<b>INSTRUCTIONS TO STUDY COORDINATORS:</b>
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1. Do not send **Section A** to the family with questionnaire. This section is to be completed by study coordinator prior to sending the completed instrument to the DCC.
2. Send instrument to study participant's family with the **GENERAL INFORMATION** page as the cover page.
3. Affix study label to **GENERAL INFORMATION** page after receiving completed questionnaire from participant's family and photocopy entire packet and maintain in the study subject's research file.  
Separate **GENERAL INFORMATION** page prior to forwarding questionnaire to the DCC.  
Do *not* send **GENERAL INFORMATION** page to the DCC.
4. Re-attach completed **Section A** to the questionnaire (pages 1-11) and send original instrument packet to DCC.

General Note: The same version of Section A should be used for both the English and Spanish questionnaires.

<b>INSTRUCTIONS TO FAMILY:</b>
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1. Having children can change people's lives. Here are some statements that people have made about living with a child. (read aloud to family member)
2. For each statement, indicate whether at the present time, you would strongly agree, agree, disagree, or strongly disagree with the statement.
3. Answer all questions in Part I.
4. We will return to beginning to ask certain questions again. Please comment if the item is:  
**Fully**  
**Partly**, or  
**Not at all** related to their child's health
5. All information is strictly confidential, and your name will not be used in any reports. This questionnaire is completely voluntary and will not affect your medical care. Please answer each question as accurately as you can.