A1. Site/Study ID #:___ ___ / P___ ___ ___ ___ A2. Date of Interview:___ ___ / ___ ___ / ___ ___ ___ ___ (Month / Day / Year) A3. Staff Initials:___ ___ ___

A5. 1. ☐ Age 3 Years 2. ☐ Age 4 Years 3. ☐ Age 5 Years 4. ☐ Age 6 Years

To DCC ☐

Parents/Caregivers (Children Ages 3 to 6)

CFQ-R

CYSTIC FIBROSIS QUESTIONNAIRE - REVISED

Understanding the impact of your child's illness and treatments on his or her everyday life can help your healthcare team keep track of your child's health and adjust his or her treatments. For this reason, we have developed a quality of life measure specifically for parents of children with cystic fibrosis. We thank you for your willingness to complete this questionnaire.

Instructions: The following questions are about the current state of your child's health, as he or she perceives it. This information will allow us to better understand how he or she feels in everyday life.
Please answer all the questions. There are no right or wrong answers! If you are not sure how to answer, choose the response that seems closest to your child's situation.

SECTION I: DEMOGRAPHICS *Please fill-in the information or check the box indicating your answer.*

A. What is your child's date of birth?
Date:

Mo Day Year

B. What is your relationship to the child?
- ☐ Mother
- ☐ Father
- ☐ Grandmother
- ☐ Grandfather
- ☐ Other relative
- ☐ Foster mother
- ☐ Foster father
- ☐ Other (Please describe) _____

C. Which of the following best describes your child's racial or ethnic background?
- ☐ Caucasian
- ☐ African American
- ☐ Hispanic
- ☐ Asian/Oriental or Pacific Islander
- ☐ Native American or Native Alaskan
- ☐ Other (please describe) _____
- ☐ Prefer not to answer this question

D. During the past two weeks, has your child been on vacation or out of school for reasons NOT related to his or her health?
- ☐ Yes ☐ No

E. What is your date of birth?
Date:

Mo Day Year

F. What is your current marital status?
- ☐ Single / never married
- ☐ Married
- ☐ Widowed
- ☐ Divorced
- ☐ Separated
- ☐ Remarried
- ☐ With a partner

G. What is the highest grade in school you have completed?
- ☐ Some high school or less
- ☐ High school diploma/GED
- ☐ Vocational school
- ☐ Some college
- ☐ College degree
- ☐ Professional or graduate degree

H. Which of the following best describes your current work status?
- ☐ Seeking work
- ☐ Working full or part time (either outside the home or at a home-based business)
- ☐ Full time homemaker
- ☐ Not working due to my health
- ☐ Not working for other reasons

 CFQ - Parent, English Version 2.0

A1. Site/Study ID #:___ ___ / P___ ___ ___ ___ A2. Date of Interview:___ ___ / ___ ___ / ___ ___ ___ ___
Month Day Year

A4. 1. ☐ Age 3 Years 2. ☐ Age 4 Years 3. ☐ Age 5 Years 4. ☐ Age 6 Years

SECTION II: QUALITY OF LIFE

Please indicate how your child has been feeling during the past two weeks by checking the box matching your response.

To what extent has your child had difficulty:	A lot of difficulty	Some difficulty	A little difficulty	No difficulty
1. Performing vigorous activities such as running or playing outside……..	☐	☐	☐	☐
2. Walking as fast as others……..	☐	☐	☐	☐
3. Climbing and jumping at a park or playground……..	☐	☐	☐	☐
4. Carrying or lifting heavy objects such as books, blocks, or school bag…	☐	☐	☐	☐
5. Climbing a flights of stairs……..	☐	☐	☐	☐

Please check the box matching your response.

*During the past **two weeks**, indicate how often your child:*	Always	Often	Sometimes	Never
6. Seemed happy……..	☐	☐	☐	☐
7. Seemed nervous or worried……..	☐	☐	☐	☐
8. Seemed tired……..	☐	☐	☐	☐
9. Seemed short-tempered……..	☐	☐	☐	☐
10. Seemed well……..	☐	☐	☐	☐
11. Seemed grouchy……..	☐	☐	☐	☐
12. Seemed energetic……..	☐	☐	☐	☐
13. Was absent or late for school or other activities because of his/her illness or treatments……..	☐	☐	☐	☐

Please circle the number indicating your answer. Please choose only one answer for each question.

*Thinking about the state of your child's health over the past **two weeks**, indicate:*

14. The extent to which your child participated in active play, sports, or other physical activites
    1. Has not participated in physical activities
    2. Has participated less than usual in physical activities
    3. Has participated as much as usual but with some difficulty
    4. Has been able to participate in physical activities without any difficulty

15. The extent to which your child has difficulty walking
    1. He or she can walk a long time without getting tired
    2. He or she can walk a long time but gets tired

A1. Site/Study ID #:___ ___ / P___ ___ ___ ___ A2. Date of Interview:___ ___ / ___ ___ / ___ ___ ___ ___
Month Day Year

A4. 1. ☐ Age 3 Years 2. ☐ Age 4 Years 3. ☐ Age 5 Years 4. ☐ Age 6 Years

3. He or she cannot walk a long time, because he or she gets tired quickly
4. He or she avoids walking whenever possible, because it's too tiring for him or her

Please check the box that matches your response to these questions.

*Thinking about your child's state of health during the past **two weeks**, indicate the extent to which each sentence is true or false for your child:*

	Very True	Somewhat True	Somewhat False	Very False
16. My child has trouble recovering after physical effort……..	☐	☐	☐	☐
17. Mealtimes are a struggle……..	☐	☐	☐	☐
18. My child's treatments get in the way of his/her activities……..	☐	☐	☐	☐
19. My child feels small compared to other kids the same age……..	☐	☐	☐	☐
20. My child feels different from other kids the same age……..	☐	☐	☐	☐
21. My child thinks that he/she is too thin……..	☐	☐	☐	☐
22. My child feels healthy……..	☐	☐	☐	☐
23. My child tends to be withdrawn……..	☐	☐	☐	☐
24. My child leads a normal life……..	☐	☐	☐	☐
25. My child has less fun than usual……..	☐	☐	☐	☐
26. My child has trouble getting along with others……..	☐	☐	☐	☐
27. My child has trouble concentrating or paying attention……..	☐	☐	☐	☐
28. My child is able to keep up with his/her activities at school or home…….	☐	☐	☐	☐
29. My child is not doing as well as usual in his/her activities……..	☐	☐	☐	☐
30. My child spends a lot of time on his/her treatments everyday……..	☐	☐	☐	☐

Please circle the number indicating your answer. Please choose only one answer for each question.

31. How difficult is it for your child to do his/her treatments (including medications) each day?
    1. Not at all
    2. A little
    3. Moderately
    4. Very

32. How do you think your child's health is now?
    1. Excellent
    2. Good
    3. Fair
    4. Poor

A1. Site/Study ID #:___ ___ / P___ ___ ___ ___ A2. Date of Interview:___ ___ / ___ ___ / ___ ___ ___ ___
Month Day Year

A4. 1. ☐ Age 3 Years 2. ☐ Age 4 Years 3. ☐ Age 5 Years 4. ☐ Age 6 Years

SECTION III: SYMPTOM DIFFICULTIES

The next set of questions is designed to determine the frequency with which your child has certain respiratory difficulties, such as coughing or shortness of breath.

*Please indicate how your child has been feeling during the past **two weeks**:*	A great deal	Somewhat	A little	Not at all
33. My child had trouble gaining weight.....	☐	☐	☐	☐
34. My child was congested.....	☐	☐	☐	☐
35. My child coughed during the day.....	☐	☐	☐	☐
36. My child had to cough up mucus.....	☐	☐	☐	☐

Go to Question 38

37. My child's mucus has been mostly:

☐ Clear ☐ Clear to yellow ☐ Yellowish-green
☐ Green with traces of blood ☐ DK

*During the past **two weeks**:*	Always	Often	Sometimes	Never
38. My child wheezed….....	☐	☐	☐	☐
39. My child had trouble breathing.....	☐	☐	☐	☐
40. My child woke up during the night because he/she was coughing.....	☐	☐	☐	☐
41. My child had gas.....	☐	☐	☐	☐
42. My child had diarrhea.....	☐	☐	☐	☐
43. My child had abdominal pain.....	☐	☐	☐	☐
44. My child has had eating problems….....	☐	☐	☐	☐

Please be sure you have answered all the questions.

THANK YOU FOR YOUR COOPERATION!