Supplement D. DSQ Pediatric (DSQ-Ped) Parent Form

This document contains the following material:

- 1. Case definition scoring rules and associated symptoms for the following criteria:
 - a. Jason et al. (2006) Pediatric Case Definition for ME and CFS
 - b. Rowe et al. (2017) Pediatric ME/CFS Case Definition
- 2. Syntax for the following case definitions:
 - a. Jason et al. (2006) Pediatric Case Definition for ME and CFS
 - b. Rowe et al. (2017) Pediatric ME/CFS Case Definition
- 3. Hard copy of the DSQ-Ped (Parent Form)

The DSQ-Ped (Parent Form) can be downloaded from the REDCap shared library. You can view the instrument here: <u>https://redcap.is.depaul.edu/surveys/?s=3FPRX49778</u>

DSQ-Ped (Parent Form) Case Definition Criteria:

Note: Results from both the parent and child forms of the DSQ-Ped should be considered when making diagnostic decisions.

Pediatric Case Definition for ME and CFS (Jason et al., 2006)

- 3+ months Fatigue (Question 15; frequency and severity scores >= 2)
 - Note: Due to challenges in measuring the 'substantial reduction in functioning' criterion among children, clinician assessment is required to determine if the child has demonstrated a significant reduction in educational, social, and/or personal activities
 - At least 1 symptom from each of the following domains (frequency and severity scores ≥ 2):
 - Post-exertional malaise (Questions 16-20)
 - Unrefreshing sleep (Questions 21-25)
 - Pain (Question 26-31; 42-45)
- At least 2 neurocognitive manifestations (Questions 32-41; frequency and severity scores >= 2)
- At least 1 symptom from 2 of the following categories (frequency and severity scores ≥ 2):
 - Autonomic (Questions 46-49)
 - Neuroendocrine (Questions 50-57)
 - Immune (Questions 58-61)

Pediatric ME/CFS Criteria (Rowe et al., 2017)

- 6+ months of illness (Question $68a \ge 6$)
- Impaired function; at least 1 of the following symptoms:
 - Question 75 (*"Yes"*)
 - Question 80 ("Yes")
- Fatigue
 - Question 15 (frequency and severity scores ≥ 2)
 - Not relieved by rest: Question 69 ("Some of it goes away" or "None of it goes away")
- Post-exertional symptoms (At least 1 symptom from Questions 16-20; frequency and severity scores >= 2)
- At least 1 symptom from 2 of the following categories (frequency and severity scores ≥ 2):
 - Sleep problems (Questions 21-25)
 - Cognitive problems (Questions 33-41)
 - Pain (Questions 26-27; 30-31; 58-59)

DSQ-Ped (Parent Form) SPSS Case Definition Syntax:

Results from both the parent and child forms of the DSQ-Ped should be considered when making diagnostic decisions.

Scoring Note: To determine which variables are associated with which items, note that variable names utilize the items numbers present in the questionnaire.

DSQ-Ped (Parent Form). * Pediatric Case Definition for ME and CFS (Jason et al., 2006)*.

Fatigue.

Note: Due to challenges in measuring the 'substantial reduction in functioning' criterion among children, clinician assessment is required to determine if the child has demonstrated a significant reduction in educational, social, and/or personal activities.

COMPUTE PedP_Fatigue = 0. EXECUTE. IF((dsqp_p_15f>= 2) & (dsqp_p_15s >= 2)) PedP_Fatigue = 1. EXECUTE.

Post-exertional malaise. COMPUTE PedP_16 = 0. EXECUTE. IF((dsqp_p_16f>= 2) & (dsqp_p_16s>= 2)) PedP_16 = 1. EXECUTE.

COMPUTE PedP_17 = 0. EXECUTE. IF((dsqp_p_17f>= 2) & (dsqp_p_17s>= 2)) PedP_17 = 1. EXECUTE.

COMPUTE PedP_18 = 0. EXECUTE. IF((dsqp_p_18f >= 2) & (dsqp_p_18s >= 2)) PedP_18 = 1. EXECUTE.

COMPUTE PedP_19 = 0. EXECUTE. IF((dsqp_p_19f >= 2) & (dsqp_p_19s >= 2)) PedP_19 = 1. EXECUTE. COMPUTE PedP 20 = 0. EXECUTE. $IF((dsqp_p_20f \ge 2) \& (dsqp_p_20s \ge 2)) PedP_20 = 1.$ EXECUTE. COMPUTE PedP PEM = 0. EXECUTE. IF(SUM(PedP 16, PedP 17, PedP 18, PedP 19, PedP 20) >= 1) PedP PEM = 1. EXECUTE. *Unrefreshing Sleep*. COMPUTE PedP 21 = 0. EXECUTE. IF((dsqp p $21f \ge 2)$ & (dsqp p $21s \ge 2$)) PedP 21 = 1. EXECUTE. COMPUTE PedP 22 = 0. EXECUTE. IF((dsqp p $22f \ge 2)$ & (dsqp_p_ $22s \ge 2$)) PedP_22 = 1. EXECUTE. COMPUTE PedP 23 = 0. EXECUTE. IF((dsqp p $23f \ge 2)$ & (dsqp p $23s \ge 2$)) PedP 23 = 1. EXECUTE. COMPUTE PedP 24 = 0. EXECUTE. IF((dsqp p $24f \ge 2)$ & (dsqp p $24s \ge 2$)) PedP 24 = 1. EXECUTE. COMPUTE PedP 25 = 0. EXECUTE. IF((dsqp p $25f \ge 2)$ & (dsqp p $25s \ge 2$)) PedP 25 = 1. EXECUTE. COMPUTE PedP Sleep = 0. EXECUTE. IF(SUM(PedP 21, PedP 22, PedP 23, PedP 24, PedP 25) ≥ 1) PedP Sleep = 1. EXECUTE. *Pain*. COMPUTE PedP 26 = 0. EXECUTE. IF((dsqp p $26f \ge 2)$ & (dsqp p $26s \ge 2$)) PedP 26 = 1. EXECUTE.

COMPUTE PedP 27 = 0. EXECUTE. IF((dsqp p $27f \ge 2)$ & (dsqp p $27s \ge 2$)) PedP 27 = 1. EXECUTE. COMPUTE PedP 28 = 0. EXECUTE. IF((dsqp p $28f \ge 2)$ & (dsqp p $28s \ge 2$)) PedP 28 = 1. EXECUTE. COMPUTE PedP 29 = 0. EXECUTE. IF((dsqp p $29f \ge 2)$ & (dsqp p $29s \ge 2$)) PedP 29 = 1. EXECUTE. COMPUTE PedP 30 = 0. EXECUTE. IF((dsqp p $30f \ge 2)$ & (dsqp p $30s \ge 2$)) PedP 30 = 1. EXECUTE. COMPUTE PedP 31 = 0. EXECUTE. IF((dsqp p $31f \ge 2)$ & (dsqp p $31s \ge 2$)) PedP 31 = 1. EXECUTE. COMPUTE PedP 42 = 0. EXECUTE. IF((dsqp p $42f \ge 2)$ & (dsqp p $42s \ge 2$)) PedP 42 = 1. EXECUTE. COMPUTE PedP 43 = 0. EXECUTE. IF((dsqp p $43f \ge 2)$ & (dsqp p $43s \ge 2$)) PedP 43 = 1. EXECUTE. COMPUTE PedP 44 = 0. EXECUTE. IF((dsqp p $44f \ge 2)$ & (dsqp_p_44s \ge 2)) PedP_44 = 1. EXECUTE. COMPUTE PedP 45 = 0. EXECUTE. IF((dsqp p $45f \ge 2)$ & (dsqp p $45s \ge 2$)) PedP 45 = 1. EXECUTE. COMPUTE PedP Pain = 0. IF(SUM(PedP 26, PedP 27, PedP 28, PedP 29, PedP 30, PedP 31, PedP 42, PedP 43, PedP 44, PedP $(45) \ge 1$) PedP Pain = 1. EXECUTE.

Neurocognitive. COMPUTE PedP 32 = 0. EXECUTE. IF((dsqp p $32f \ge 2)$ & (dsqp p $32s \ge 2$)) PedP 32 = 1. EXECUTE. COMPUTE PedP 33 = 0. EXECUTE. IF((dsqp p $33f \ge 2)$ & (dsqp p $33s \ge 2$)) PedP 33 = 1. EXECUTE. COMPUTE PedP 34 = 0. EXECUTE. IF((dsqp p $34f \ge 2)$ & (dsqp p $34s \ge 2$)) PedP 34 = 1. EXECUTE. COMPUTE PedP 35 = 0. EXECUTE. $IF((dsqp_p_35f \ge 2) \& (dsqp_p_35s \ge 2)) PedP_35 = 1.$ EXECUTE. COMPUTE PedP 36 = 0. EXECUTE. IF((dsqp p $36f \ge 2)$ & (dsqp p $36s \ge 2$)) PedP 36 = 1. EXECUTE. COMPUTE PedP 37 = 0. EXECUTE. IF(($dsqp_p_37f \ge 2$) & ($dsqp_p_37s \ge 2$)) PedP_37 = 1. EXECUTE. COMPUTE PedP 38 = 0. EXECUTE. IF((dsqp p $38f \ge 2)$ & (dsqp p $38s \ge 2$)) PedP 38 = 1. EXECUTE. COMPUTE PedP 39 = 0. EXECUTE. IF((dsqp p $39f \ge 2)$ & (dsqp p $39s \ge 2$)) PedP 39 = 1. EXECUTE. COMPUTE PedP 40 = 0. EXECUTE. IF((dsqp p 40f >= 2) & (dsqp p 40s >= 2)) PedP 40 = 1. EXECUTE. COMPUTE PedP 41 = 0. EXECUTE.

IF((dsqp p $41f \ge 2)$ & (dsqp p $41s \ge 2$)) PedP 41 = 1. EXECUTE. COMPUTE PedP Cognitive = 0. EXECUTE. IF(SUM(PedP 32, PedP 33, PedP 34, PedP 35, PedP 36, PedP 37, PedP 38, PedP 39, PedP 40, PedP 41) >=2) PedP Cognitive = 1. EXECUTE. *Autonomic*. COMPUTE PedP 46 = 0. EXECUTE. $IF((dsqp_p_46f \ge 2) \& (dsqp_p_46s \ge 2)) PedP_46 = 1.$ EXECUTE. COMPUTE PedP 47 = 0. EXECUTE. IF((dsqp p $47f \ge 2)$ & (dsqp p $47s \ge 2$)) PedP 47 = 1. EXECUTE. COMPUTE PedP 48 = 0. EXECUTE. $IF((dsqp_p_48f \ge 2) \& (dsqp_p_48s \ge 2)) PedP_48 = 1.$ EXECUTE. COMPUTE PedP 49 = 0. EXECUTE. IF((dsqp p $49f \ge 2)$ & (dsqp p $49s \ge 2$)) PedP 49 = 1. EXECUTE. COMPUTE PedP Autonomic = 0. EXECUTE. IF(SUM(PedP 46, PedP 47, PedP 48, PedP 49) ≥ 1) PedP Autonomic = 1. EXECUTE. *Neuroendocrine*. COMPUTE PedP 50 = 0. EXECUTE. IF((dsqp p $50f \ge 2)$ & (dsqp p $50s \ge 2$)) PedP 50 = 1. EXECUTE. COMPUTE PedP 51 = 0. EXECUTE. IF((dsqp p $51f \ge 2)$ & (dsqp p $51s \ge 2$)) PedP 51 = 1. EXECUTE. COMPUTE PedP 52 = 0.

EXECUTE. IF((dsqp p $52f \ge 2)$ & (dsqp p $52s \ge 2$)) PedP 52 = 1. EXECUTE. COMPUTE PedP_53 = 0. EXECUTE. IF((dsqp p $53f \ge 2)$ & (dsqp p $53s \ge 2$)) PedP 53 = 1. EXECUTE. COMPUTE PedP 54 = 0. EXECUTE. IF((dsqp p $54f \ge 2)$ & (dsqp p $54s \ge 2$)) PedP 54 = 1. EXECUTE. COMPUTE PedP 55 = 0. EXECUTE. IF((dsqp p $55f \ge 2)$ & (dsqp p $55s \ge 2$)) PedP 55 = 1. EXECUTE. COMPUTE PedP_56 = 0. EXECUTE. $IF((dsqp_p_56f \ge 2) \& (dsqp_p_56s \ge 2)) PedP_56 = 1.$ EXECUTE. COMPUTE PedP 57 = 0. EXECUTE. IF((dsqp p $57f \ge 2)$ & (dsqp p $57s \ge 2$)) PedP 57 = 1. EXECUTE. COMPUTE PedP Neuroendo = 0. EXECUTE. IF(SUM(PedP_50, PedP_51, PedP_52, PedP_53, PedP_54, PedP_55, PedP_56, PedP_57) >= 1) PedP Neuroendo = 1. EXECUTE. *Immune* COMPUTE PedP 58 = 0. EXECUTE. IF((dsqp p $58f \ge 2)$ & (dsqp p $58s \ge 2$)) PedP 58 = 1. EXECUTE. COMPUTE PedP 59 = 0. EXECUTE. IF((dsqp p $59f \ge 2)$ & (dsqp p $59s \ge 2$)) PedP 59 = 1. EXECUTE. COMPUTE PedP 60 = 0. EXECUTE.

IF((dsqp_p_60f >= 2) & (dsqp_p_60s >= 2)) PedP_60 = 1. EXECUTE.

COMPUTE PedP_61 = 0. EXECUTE. IF((dsqp_p_61f>= 2) & (dsqp_p_61s>= 2)) PedP_61 = 1. EXECUTE.

COMPUTE PedP_Immune = 0. EXECUTE. IF(SUM(PedP_58, PedP_59, PedP_60, PedP_61) >= 1) PedP_Immune = 1. EXECUTE.

Jason et al. (2006) Pediatric Case Definition for ME and CFS. COMPUTE PedP_ANI2 = 0. EXECUTE. IF(SUM(PedP_Autonomic, PedP_Neuroendo, PedP_Immune) >= 2) PedP_ANI2 = 1. EXECUTE.

COMPUTE PedP_Jason = 0. EXECUTE. IF(SUM(PedP_Fatigue, PedP_PEM, PedP_Sleep, PedP_Pain, PedP_Cognitive, PedP_ANI2) = 6) PedP_Jason = 1. EXECUTE.

VALUE LABELS PedP_Jason 0 'Does not meet Jason et al Pediatric ME and CFS Criteria' 1 'Meets Jason et al Pediatric ME and CFS Criteria'. EXECUTE. *DSQ-Ped (Parent Form)*. * Pediatric ME/CFS Criteria (Rowe et al., 2017)*.

Six months of illness. COMPUTE RoweP_Six = 0. EXECUTE. IF(dsqp_p_68a >= 6) RoweP_Six = 1. EXECUTE.

Impaired Function. COMPUTE RoweP_75 = 0. EXECUTE. IF(dsqp_p_75 = 1) RoweP_75 = 1. EXECUTE.

COMPUTE RoweP_80 = 0. EXECUTE. IF(dsqp_p_80 = 1) RoweP_80 = 1. EXECUTE.

COMPUTE RoweP_Function = 0. EXECUTE. IF((RoweP_75 = 1) | (RoweP_80 = 1)) RoweP_Function = 1. EXECUTE.

Fatigue. COMPUTE RoweP_15 = 0. EXECUTE. IF((dsqp_p_15f>= 2) & (dsqp_p_15s >= 2)) RoweP_15 = 1. EXECUTE.

COMPUTE RoweP_69 = 0. EXECUTE. IF((dsqp_p_69 = 2) | (dsqp_p_69 = 3)) RoweP_69 = 1. EXECUTE.

COMPUTE RoweP_Fatigue = 0. EXECUTE. IF(SUM(RoweP_15, RoweP_69) = 2) RoweP_Fatigue = 1. EXECUTE. *Post-exertional malaise*. COMPUTE RoweP 16 = 0. EXECUTE. $IF((dsqp_p_16f \ge 2) \& (dsqp_p_16s \ge 2)) RoweP_16 = 1.$ EXECUTE. COMPUTE RoweP 17 = 0. EXECUTE. IF((dsqp p $17f \ge 2)$ & (dsqp p $17s \ge 2$)) RoweP 17 = 1. EXECUTE. COMPUTE RoweP 18 = 0. EXECUTE. $IF((dsqp_p_18f \ge 2) \& (dsqp_p_18s \ge 2)) RoweP_18 = 1.$ EXECUTE. COMPUTE RoweP 19 = 0. EXECUTE. IF((dsqp p $19f \ge 2)$ & (dsqp p $19s \ge 2$)) RoweP 19 = 1. EXECUTE. COMPUTE RoweP 20 = 0. EXECUTE. IF((dsqp p $20f \ge 2)$ & (dsqp p $20s \ge 2$)) RoweP 20 = 1. EXECUTE. COMPUTE RoweP PEM = 0. EXECUTE. IF(SUM(RoweP 16, RoweP 17, RoweP 18, RoweP 19, RoweP 20) ≥ 1) RoweP PEM = 1. EXECUTE. *Sleep Problems*. COMPUTE RoweP 21 = 0. EXECUTE. IF((dsqp p $21f \ge 2)$ & (dsqp p $21s \ge 2$)) RoweP 21 = 1. EXECUTE. COMPUTE RoweP 22 = 0. EXECUTE. IF((dsqp p $22f \ge 2)$ & (dsqp p $22s \ge 2$)) RoweP 22 = 1. EXECUTE. COMPUTE RoweP 23 = 0. EXECUTE. IF((dsqp p $23f \ge 2)$ & (dsqp p $23s \ge 2$)) RoweP 23 = 1. EXECUTE. COMPUTE RoweP 24 = 0.

EXECUTE. IF((dsqp p $24f \ge 2)$ & (dsqp p $24s \ge 2$)) RoweP 24 = 1. EXECUTE. COMPUTE RoweP 25 = 0. EXECUTE. IF((dsqp p $25f \ge 2)$ & (dsqp p $25s \ge 2$)) RoweP 25 = 1. EXECUTE. COMPUTE RoweP Sleep = 0. EXECUTE. IF(SUM(RoweP 21, RoweP 22, RoweP 23, RoweP 24, RoweP 25) ≥ 1) RoweP Sleep = 1. EXECUTE. *Cognitive Problems*. COMPUTE RoweP 33 = 0. EXECUTE. IF((dsqp p $33f \ge 2)$ & (dsqp p $33s \ge 2$)) RoweP 33 = 1. EXECUTE. COMPUTE RoweP 34 = 0. EXECUTE. IF((dsqp p $34f \ge 2)$ & (dsqp p $34s \ge 2$)) RoweP 34 = 1. EXECUTE. COMPUTE RoweP 35 = 0. EXECUTE. IF((dsqp p $35f \ge 2)$ & (dsqp p $35s \ge 2$)) RoweP 35 = 1. EXECUTE. COMPUTE RoweP 36 = 0. EXECUTE. IF((dsqp p $36f \ge 2)$ & (dsqp p $36s \ge 2$)) RoweP 36 = 1. EXECUTE. COMPUTE RoweP $_37 = 0$. EXECUTE. IF((dsqp p $37f \ge 2)$ & (dsqp p $37s \ge 2$)) RoweP 37 = 1. EXECUTE. COMPUTE RoweP 38 = 0. EXECUTE. IF((dsqp p $38f \ge 2)$ & (dsqp p $38s \ge 2$)) RoweP 38 = 1. EXECUTE. COMPUTE RoweP 39 = 0. EXECUTE. IF((dsqp p $39f \ge 2)$ & (dsqp p $39s \ge 2$)) RoweP 39 = 1.

EXECUTE.

COMPUTE RoweP 40 = 0. EXECUTE. IF((dsqp p $40f \ge 2)$ & (dsqp p $40s \ge 2$)) RoweP 40 = 1. EXECUTE. COMPUTE RoweP 41 = 0. EXECUTE. IF((dsqp p $41f \ge 2)$ & (dsqp p $41s \ge 2$)) RoweP 41 = 1. EXECUTE. COMPUTE RoweP Cognitive = 0. EXECUTE. IF(SUM(RoweP 33, RoweP 34, RoweP 35, RoweP 36, RoweP_37, RoweP_38, RoweP_39, RoweP 40, RoweP 41) ≥ 1) RoweP Cognitive = 1. EXECUTE. *Pain*. COMPUTE RoweP 26 = 0. EXECUTE. IF((dsqp p $26f \ge 2)$ & (dsqp p $26s \ge 2$)) RoweP 26 = 1. EXECUTE. COMPUTE RoweP 27 = 0. EXECUTE. IF((dsqp p $27f \ge 2)$ & (dsqp p $27s \ge 2$)) RoweP 27 = 1. EXECUTE. COMPUTE RoweP 30 = 0. EXECUTE. IF((dsqp p $30f \ge 2)$ & (dsqp p $30s \ge 2$)) RoweP 30 = 1. EXECUTE. COMPUTE RoweP 31 = 0. EXECUTE. IF((dsqp p $31f \ge 2)$ & (dsqp p $31s \ge 2$)) RoweP 31 = 1. EXECUTE. COMPUTE RoweP 58 = 0. EXECUTE. IF((dsqp p $58f \ge 2)$ & (dsqp p $58s \ge 2$)) RoweP 58 = 1. EXECUTE. COMPUTE RoweP 59 = 0. EXECUTE. IF((dsqp p $59f \ge 2)$ & (dsqp p $59s \ge 2$)) RoweP 59 = 1. EXECUTE.

COMPUTE RoweP_Pain = 0. EXECUTE. IF(SUM(RoweP_26, RoweP_27, RoweP_30, RoweP_31, RoweP_58, RoweP_59) >= 1) RoweP_Pain = 1. EXECUTE.

Pediatric ME/CFS Criteria (Rowe et al., 2017).

COMPUTE RoweP_SCP2 = 0. EXECUTE. IF(SUM(RoweP_Sleep, RoweP_Cognitive, RoweP_Pain) >= 2) RoweP_SCP2 = 1. EXECUTE.

COMPUTE Rowe_Parent = 0. EXECUTE. IF(SUM(RoweP_Six, RoweP_Function, RoweP_Fatigue, RoweP_PEM, RoweP_SCP2) = 5) Rowe_Parent = 1. EXECUTE.

VALUE LABELS Rowe_Parent 0 ' Does Not Meet Rowe et al Pediatric MECFS Criteria' 1 'Meets Rowe et al Pediatric MECFS Criteria'. EXECUTE.

DePaul Symptom Questionnaire – Pediatric (Parent Report Form) DSQ-Ped (Parent)

Participant ID: _____

- 1. Today's Date: _____
- 2. Child's Date of Birth:
- 3. Child's Age: _____
- 4. Child's Gender:
 - o Male
 - o Female
 - o Other
 - Prefer not to respond

5. Child's Grade in School:

- o Preschool
- Kindergarten
- \circ 1st Grade
- \circ 2nd Grade
- \circ 3rd Grade
- \circ 4th Grade
- \circ 5th Grade

- \circ 6th Grade
- $\circ \quad 7^{th} \, Grade$
- o 8th Grade
- o 9th Grade (Freshman)
- \circ 10th Grade (Sophomore)
- \circ 11th Grade (Junior)
- \circ 12th Grade (Senior)
- Ungraded

a. If ungraded, how many years has your child attended school?

- 6. Do you have any other children?
 - o Yes
 - o No

a. If so, how many additional children do you have?

b. How many of your children are under 18 years old?

- 7. How many people live in your home (including you)?
- 8. What is the highest degree or level of education you have completed?
 - Less than high school
 - Some high school
 - High school or GED
 - o Partial college (at least one year) or specialized training
 - Standard college degree
 - o Graduate or professional degree, including Master's and Doctorate
- 9. What category best describes your annual household income?
 - o Less than \$24,999
 - \$25,000 \$49,999
 - o \$50,000 \$99,999
 - o \$100,000 \$149,999
 - o \$150,000 \$199,999
 - \$200,000 \$249,999
 - \$250,000 or more
 - Prefer not to respond
- 10. How would you describe your current employment status?
 - Employed full-time
 - Employed part-time
 - Unemployed / Looking for work
 - o Student
 - Homemaker
 - o Retired
- 11. What is your current marital status?
 - Married / Living with partner
 - o Separated
 - \circ Widowed
 - o Divorced
 - o Never married

- 12. What is your race / ethnicity (check all that apply)?
 - □ American Indian or Alaskan Native
 - Asian or Pacific Islander
 - □ Black / African American
 - □ White / Caucasian
 - \Box Prefer not to respond
 - \Box Other (please specify)
 - a. If other, please specify:

13. Are you of Latino or Hispanic origin?

- o Yes
- o No

14. What is your religious affiliation?

- Atheist or Agnostic
- o Buddhist
- o Christian
- o Hindu
- o Jewish
- o Muslim
- Prefer not to respond
- Other (please specify)
- a. If other, please specify: _____

For the next questions, think about your child over the **past 3 months**. Circle how often your child has had each symptom (frequency) and how much each symptom has bothered him/her (severity).

Please circle **one number for frequency** and **one number for severity**, using the following scales:

<u>Frequency:</u>	<u>Severity:</u>
Throughout the past 3 months , how <u>often</u> has your child had this symptom?	Throughout the past 3 months , how <u>much</u> has this symptom bothered your child?
For each symptom listed below, circle a number from: 0 = none of the time 1 = a little of the time 2 = about half the time 3 = most of the time 4 = all of the time	For each symptom listed below, circle a number from: 0 = no problem 1 = mild 2 = moderate 3 = severe 4 = very severe

Symptom	Frequency:	Severity:
15. Fatigue / Extreme tiredness	0 1 2 3 4	0 1 2 3 4
16. Body feels heavy after starting to exercise	0 1 2 3 4	0 1 2 3 4
17. Feeling sore / very tired after everyday activities, like walking around the house	0 1 2 3 4	0 1 2 3 4
18. Mind is tired after just a little effort	0 1 2 3 4	0 1 2 3 4
19. A little bit of exercise makes your child's body tired	0 1 2 3 4	0 1 2 3 4
20. Child's body is tired or he/she feels sick after a little bit of activity	0 1 2 3 4	0 1 2 3 4
21. Feeling tired after he/she wakes up in the morning	0 1 2 3 4	0 1 2 3 4
22. Needing to nap daily	0 1 2 3 4	0 1 2 3 4
23. Problems falling asleep	0 1 2 3 4	0 1 2 3 4
24. Problems staying asleep	0 1 2 3 4	0 1 2 3 4
25. Waking up early in the morning (like 3:00 am)	0 1 2 3 4	0 1 2 3 4
26. Pain or aching in muscles	0 1 2 3 4	0 1 2 3 4
27. Pain / Stiffness / Tenderness in more than one joint, without swelling or redness	0 1 2 3 4	0 1 2 3 4
28. Eye pain	0 1 2 3 4	0 1 2 3 4
29. Chest pain / Heartburn	0 1 2 3 4	0 1 2 3 4
30. Abdomen / Stomach pain	0 1 2 3 4	0 1 2 3 4
31. Headaches	0 1 2 3 4	0 1 2 3 4
32. Muscle twitches	0 1 2 3 4	0 1 2 3 4

Symptom	Frequency:	Severity:
33. Problems remembering things	0 1 2 3 4	0 1 2 3 4
34. Difficulty paying attention for a long period of time	0 1 2 3 4	0 1 2 3 4
35. Difficulty finding the right word to say	0 1 2 3 4	0 1 2 3 4
36. Difficulty understanding things	0 1 2 3 4	0 1 2 3 4
37. Only able to focus on one thing at a time	0 1 2 3 4	0 1 2 3 4
38. Slowness of thought	0 1 2 3 4	0 1 2 3 4
39. Absent-mindedness or forgetfulness	0 1 2 3 4	0 1 2 3 4
40. Frequently losing train of thought	0 1 2 3 4	0 1 2 3 4
41. Trouble with math or numbers	0 1 2 3 4	0 1 2 3 4
42. Nausea	0 1 2 3 4	0 1 2 3 4
43. Upset stomach	0 1 2 3 4	0 1 2 3 4
44. Vomiting	0 1 2 3 4	0 1 2 3
45. Ringing in ears	0 1 2 3 4	0 1 2 3
46. Feeling unsteady on feet, like he/she might fall	0 1 2 3 4	0 1 2 3
47. Shortness of breath or trouble catching his/her breath	0 1 2 3 4	0 1 2 3
48. Dizziness	0 1 2 3 4	0 1 2 3
49. Irregular heart beats	0 1 2 3 4	0 1 2 3
50. Losing or gaining weight without trying	0 1 2 3 4	0 1 2 3
51. Sweating hands	0 1 2 3 4	0 1 2 3
52. Not wanting to eat	0 1 2 3 4	0 1 2 3
53. Night sweats	0 1 2 3 4	0 1 2 3
54. Feeling chills or shivers	0 1 2 3 4	0 1 2 3
55. Feeling hot or cold for no reason	0 1 2 3 4	0 1 2 3
56. Feeling like he/she has a high temperature	0 1 2 3 4	0 1 2 3
57. Feeling like he/she has a low temperature	0 1 2 3 4	0 1 2 3
58. Sore throat	0 1 2 3 4	0 1 2 3
59. Tender / sore lymph nodes	0 1 2 3 4	0 1 2 3
60. Fever and sweats	0 1 2 3 4	0 1 2 3
61. Some smells, foods, or chemicals make your child feel sick	0 1 2 3 4	0 1 2 3
62. Rashes	0 1 2 3 4	0 1 2 3
63. Allergies	0 1 2 3 4	0 1 2 3 4

- 64. When your child **first became sick**, what were his/her worst three symptoms? Please select from the list above, or if your child is not sick, write "my child is not ill."
 - a. Worst symptom: _____
 - b. Second-worst symptom:
 - c. Third-worst symptom: _____
- 65. <u>**Right now**</u>, what are his/her worst three symptoms? Please select from the list above, or if your child is not sick, write "my child is not ill."
 - a. Worst symptom: _____
 - b. Second-worst symptom:
 - c. Third-worst symptom: _____

66. How long did it take for your child's problem with fatigue or tiredness to get started?

- Rapidly within 24 hours
- Over 1 week
- Over 1 month
- Over 2-3 months
- Over 4-6 months
- Over 7-11 months
- Over 1-2 years
- Longer than 2 years
- My child has always experienced fatigue
- My child does not have fatigue
- 67. If your child has headaches now, does he/she get them more often, in a different place, or do the headaches feel worse than they did in the past?
 - o Headaches happen more often
 - o Headaches feel worse / more severe
 - Headaches are in a different place / spot
 - My child doesn't have headaches
- 68. Has your child been experiencing problems with fatigue / extreme tiredness for <u>at least one</u> <u>month</u>?
 - o Yes
 - o No
 - a. If yes, for about how many months?

69. If your child rests, does all of his/her fatigue go away, some of it go away, or none of it go away?

- All of it goes away
- Some of it goes away
- None of it goes away
- My child does not have fatigue
- a. If all or some of it goes away, for <u>how many hours</u> does your child have to rest before his/her fatigue gets better? _____

70. Does your child participate in any hobbies or activities outside of school?

- o Yes
- o No
- a. If no, why? Select all that apply.
 - \Box Not interested
 - \Box No time
 - □ Would like to, but cannot because of problems with fatigue / energy
 - □ Cannot because hobbies or activities make symptoms worse
- 71. Does your child limit or cut back activity levels to avoid feeling even more tired?
 - o Yes
 - o No
- 72. How would you describe the way your child's fatigue problem is changing over time?
 - My child's fatigue is getting worse
 - My child has good and bad periods
 - There is no change
 - My child's fatigue is getting better
 - My child does not have fatigue
- 73. Do your child's symptoms change over time?
 - o Yes
 - o No

- 74. Did your child's fatigue or energy problems start after he/she experienced any of the following? Check all that apply. If you check an option, please provide more details in the appropriate blank (e.g., year it began, treatment history, etc.)
 - \square a. An infectious illness
- \square b. An accident \Box c. A trip or vacation _____ □ d. An immunization (shot at doctor's office) □ e. Surgery □ f. Severe stress (bad or unhappy events) □ g. Other (please describe below) 75. Since the start of your child's problems with fatigue or energy, have your child's symptoms caused him/her to reduce the time he/she does activities by 50% or more? o Yes
 - o No
 - Not having a problem with fatigue / energy
- 76. Does your child seem to catch illnesses more easily than other people his/her age?
 - a. Yes
 - b. No

- 77. Does it seem to take your child longer to get better after he/she is sick than other people his/her age?
 - a. Yes
 - b. No

78. Is your child more uncomfortable than other people his/her age when it is extremely hot or cold?

- a. Yes
- b. No
- 79. Thinking about the past month, about how many **hours per week** in a typical week has your child spent on:
 - a. School / School activities _____
 - b. Sports / Recreational activities _____
 - c. Activities with friends and family _____
 - d. Work activities _____
- 80. In the past 4 weeks, has your child had to reduce the number of hours he/she previously spent (prior to illness) on school, sports or recreational activities, activities with friends or family, or work because of health or problems with fatigue / energy?
 - o Yes
 - o No
 - Not having problems with fatigue / energy

If you answered "Yes" to the previous question, <u>before</u> your child's fatigue/energyrelated problems, approximately how many hours per week did he/she used to spend on:

- a. School / School activities _____
- b. Sports / Recreational activities _____
- c. Activities with friends and family _____
- d. Work activities _____

- 81. In a typical week, please rate the amount of energy your child has available using a scale from 1 to 100, where 1 = no energy and 100 = a lot of energy: _____
- 82. In a typical week, please rate the amount of energy your child uses on a scale from 1 to 100, where 1 = no energy and 100 = a lot of energy: ______
- 83. In a typical week, please rate the amount of <u>fatigue</u> your child has using a scale from 1 to 100, where 1 = no fatigue and 100 = very bad fatigue: _____
- 84. Does your child have any medical illnesses that might be causing his/her symptoms?
 - o Yes
 - o No
 - a. If yes, please name the illnesses and the year they began:

b. For which of these medical illnesses is your child currently receiving treatment? Please list the illness(es) and associated treatment(s):

- 85. Is your child currently taking any medications (over the counter or prescription)?
 - o Yes
 - o No
 - a. If yes, what medications?

86. Do you think any medications are causing your child's problem with fatigue / energy?

- o Yes
- o No
- a. If yes, which medications?

87. Do you think anything in your child's personal life or environment is causing your child's problem with fatigue/energy?

- o Yes
- o No
- Not having problems with fatigue / energy
- a. If yes, please describe:

- 88. Has your child been diagnosed with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?
 - o Yes
 - o No

a. If yes, in what year was he/she diagnosed?

- 89. Does your child currently have a diagnosis of Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?
 - o Yes
 - o No
 - a. If your child has ever been diagnosed with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis, who diagnosed him/her? Select all that apply.
 - $\hfill\square$ Medical Doctor
 - □ Alternative Practitioner
 - □ Self-diagnosed

- 90. Have any of your child's family members been diagnosed with Chronic Fatigue Syndrome or Myalgic Encephalomyelitis?
 - o Yes
 - o No
 - a. If Yes, please list their relation to your child and current age:

- 91. Did your child experience any of the following symptoms regularly and repeatedly in the months and years before his/her fatigue / energy problems began? Select all that apply.
 - \Box Sore throat
 - □ Tender / Sore lymph nodes
 - □ Unrefreshing sleep
 - □ Impaired memory and concentration
 - □ Prolonged fatigue following physical or mental exertion
 - \square Muscle pain
 - □ Headaches
 - \Box Joint pain
 - $\hfill\square$ Not having a problem with fatigue / energy
- 92. Have you ever consulted a medical doctor or health professional about your child's fatigue / energy problem?
 - o Yes
 - o No
- 93. Do you currently have a medical doctor overseeing your child's symptoms?
 - o Yes
 - o No
- 94. What do you think is the cause of your child's problem with fatigue / energy?
 - Definitely physical
 - Mainly physical
 - Equally physical / psychological
 - Mainly psychological
 - Definitely psychological
 - Not having a problem with fatigue / energy

95.	. Has your child every been diagnosed or treated for any of the following conditions? If yes,
	please provide more details in the appropriate blank, including year of diagnosis and history of
	treatment.

a. Major depressive disorder

b.	Major depressive disorder with melancholic features
c.	Bipolar disorder (manic-depression)
d.	Anxiety
e.	Schizophrenia
f.	Eating disorder
g.	Substance abuse
h.	Multiple chemical sensitivities
i.	Fibromyalgia
j.	Allergies
k.	Other

1. No diagnosis / treatment