Form Approved
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10a

Multi-Site Clinical Assessment of CFS in Children and Adolescents

CDC Symptom Inventory: For Baseline Subjects

Subject ID Number: _____

Month and Year of Birth (MM/YY): _____

Start Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Complete Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Symptom Checklist – Form A

1. In what month and year did your fatiguing illness begin?

Month_____ Year_____ **(If you cannot remember, proceed to 1a.)**

1a. If you cannot remember the month and/or year in which your illness began: Have you been experiencing this fatiguing illness for 6 months or longer?

- ❑ 1 Yes
- ❑ 2 No
- ❑ 8 Don't know
- ❑ 7 Refused

2. When you are fatigued, does rest make your fatigue better?

- ❑ 1 Yes, a lot
- ❑ 2 Yes, a little
- ❑ 3 No, not very much
- ❑ 4 No, not at all

3. Has your fatiguing illness substantially limited your ability to pursue your usual educational activities?

- ❑ 1 Yes
- ❑ 2 No
- ❑ 3 Not applicable

4. Has your fatiguing illness substantially limited your social activities?

- ❑ 1 Yes
- ❑ 2 No
- ❑ 3 Not applicable

5. Has your fatiguing illness substantially limited your recreational activities (like sports)?

- ❑ 1 Yes
- ❑ 2 No
- ❑ 3 Not applicable

CDC Symptom Inventory

These questions are about physical symptoms that you may have experienced during the past month.

Fatigue

C.1 During the past month, have you had fatigue, tiredness, or exhaustion?

- ❑ 1 Yes
- ❑ 2 No ⟶ **(Skip to C.1f)**

C.1a During the past month, how often have you had fatigue, tiredness or exhaustion?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.1b During the past month, how bad was your fatigue, tiredness or exhaustion?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.1c Prior to this <u>past month</u>, for how long had you had fatigue, tiredness or exhaustion?

- ❑ 1 Less than 3 months → **(Skip to C.1e)**
- ❑ 2 3 – 6 months → **(Skip to C.1e)**
- ❑ 3 6 – 12 months → **(Skip to C.1e)**
- ❑ 4 More than 12 months

C.1d For how many <u>years</u> have you had fatigue, tiredness or exhaustion?

_____ Record Number of Years

C.1e Do you consider your fatigue, tiredness or exhaustion to <u>currently</u> be part of your ill-health?

- ❑ 1 Yes
- ❑ 2 No

C.1f Has fatigue, tiredness or exhaustion been a part of your ill-health <u>in the past</u>?

- ❑ 1 Yes
- ❑ 2 No

C.1g When this fatigue, tiredness, or exhaustion began, would you say that it came on all of a sudden, or slowly over time?

- ❑1 All of sudden
- ❑2 Slowly over time
- ❑6 Not applicable
- ❑8 Don't know

Sore Throat

C.2 During the past month, have you had a sore throat?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.3)**

C.2a During the past month, how often have you had a sore throat?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.2b During the past month, how bad was your sore throat?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.2c Prior to this past month, for how long had you had a sore throat?

- ❑ 1 Less than 3 months → **(Skip to C.3)**
- ❑ 2 3 – 6 months → **(Skip to C.3)**
- ❑ 3 6 – 12 months → **(Skip to C.3)**
- ❑ 4 More than 12 months

C.2d For how many years have you had a sore throat?

_____ Record Number of Years

Tender Lymph Nodes and Swollen Glands

C.3 During the past month, have you had tender lymph nodes or swollen glands in your neck or armpits?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.4)**

C.3a During the past month, how often have you had tender lymph nodes or swollen glands?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.3b During the past month, how tender were your lymph nodes or how swollen were your glands?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.3c Prior to this past month, how long had you had tender lymph nodes or swollen glands?

- ❑ 1 Less than 3 months → **(Skip to C.4)**
- ❑ 2 3 – 6 months → **(Skip to C.4)**
- ❑ 3 6 – 12 months → **(Skip to C.4)**
- ❑ 4 More than 12 months

C.3d For how many years have you had tender lymph nodes or swollen glands?

_____ Record Number of Years

Fatigue After Exertion

C.4 During the past month, have you been unusually fatigued or unwell for at least one day after exerting yourself in any way?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.5)**

C.4a During the past month, how often have you had unusual fatigue after exertion?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.4b During the past month, how bad was your unusual fatigue after exertion?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.4c Prior to this past month, for how long had you had unusual fatigue after exertion?

- ❑ 1 Less than 3 months → **(Skip to C.5)**
- ❑ 2 3 – 6 months → **(Skip to C.5)**
- ❑ 3 6 – 12 months → **(Skip to C.5)**
- ❑ 4 More than 12 months

→ **C.4d For how many years have you had unusual fatigue after exertion?**

_____ Record Number of Years

Muscle Aches and Pains

C.5 During the past month, have you had muscle aches or muscle pain?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.6)**

C.5a During the past month, how often have you had muscle aches or muscle pains?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.5b During the past month, how bad were your muscle aches or muscle pains?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.5c Prior to this past month, for how long have you had muscle aches or muscle pains?

- ❑ 1 Less than 3 months → **(Skip to C.6)**
- ❑ 2 3 – 6 months → **(Skip to C.6)**
- ❑ 3 6 – 12 months → **(Skip to C.6)**
- ❑ 4 More than 12 months

→ **C.5d For how many years have you had muscle aches or muscle pains?**

_____ Record Number of Years

Joint Pain

C.6 During the past month, have you had pain in several joints?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.7)**

C.6a During the past month, how often have you had joint pain?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.6b During the past month, how bad was the joint pain?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.6c Prior to this past month, for how long had you had joint pain?

- ❑ 1 Less than 3 months → **(Skip to C.7)**
- ❑ 2 3 – 6 months → **(Skip to C.7)**
- ❑ 3 6 – 12 months → **(Skip to C.7)**
- ❑ 4 More than 12 months

→ **C.6d For how many years have you had joint pain?**

_____ Record Number of Years

Unrefreshing Sleep

C.7 During the past month, has unrefreshing sleep been a problem for you?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.8)**

C.7a During the past month, how often have you had unrefreshing sleep?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.7b During the past month, how much of a problem was unrefreshing sleep?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.7c Prior to this past month, for how long had you had unrefreshing sleep?

- ❑ 1 Less than 3 months → **(Skip to C.8)**
- ❑ 2 3 – 6 months → **(Skip to C.8)**
- ❑ 3 6 – 12 months → **(Skip to C.8)**
- ❑ 4 More than 12 months

→ **C.7d For how many years have you had unrefreshing sleep?**

_____ Record Number of Years

Headaches

C.8 During the past month, have you had headaches?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.9)**

C.8a During the past month, how often have you had headaches?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.8b During the past month, how bad were your headaches?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.8c Prior to this past month, for how long had you had headaches?

- ❑ 1 Less than 3 months → **(Skip to C.9)**
- ❑ 2 3 – 6 months → **(Skip to C.9)**
- ❑ 3 6 – 12 months → **(Skip to C.9)**
- ❑ 4 More than 12 months

→ **C.8d For how many years have you headaches?**

_____ Record Number of Years

Memory Problems

C.9 During the past month, have you had forgetfulness or memory problems that caused you to substantially cut back on your activities?

- ❑ 1 Yes
- ❑ 2 No ⟶ **(Skip to C.10)**

C.9a During the past month, how often have you had forgetfulness or memory problems?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.9b During the past month, how bad were your forgetfulness or memory problems?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.9c Prior to this past month, for how long had you forgetfulness or memory problems?

- ❑ 1 Less than 3 months ⟶ **(Skip to C.10)**
- ❑ 2 3 – 6 months ⟶ **(Skip to C.10)**
- ❑ 3 6 – 12 months ⟶ **(Skip to C.10)**
- ❑ 4 More than 12 months

C.9d For how many years have you had forgetfulness or memory problems?

_____ Record Number of Years

Concentration

C.10 During the past month, have you had difficulty with thinking or concentrating that caused you to substantially cut back on your activities?

- ❑ 1 Yes
- ❑ 2 No ⟶ **(Skip to C.11)**

C.10a During the past month, how often have you had difficulty with thinking or concentrating?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.10b During the past month, how bad was your difficulty with thinking or concentrating?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.10c Prior to this past month, for how long had you had difficulty with thinking or concentrating?

- ❑ 1 Less than 3 months ⟶ **(Skip to C.11)**
- ❑ 2 3 – 6 months ⟶ **(Skip to C.11)**
- ❑ 3 6 – 12 months ⟶ **(Skip to C.11)**
- ❑ 4 More than 12 months

C.10d For how many years have you had difficulty with thinking or concentrating?

_____ Record Number of Years

Stomach or Abdominal Pain

C.11 During the past month, have you had stomach or abdominal pain?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.12)**

C.11a During the past month, how often have you had stomach or abdominal pain?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.11b During the past month, how bad was your stomach or abdominal pain?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.11c Prior to this past month, for how long had you had stomach or abdominal pain?

- ❑ 1 Less than 3 months → **(Skip to C.12)**
- ❑ 2 3 – 6 months → **(Skip to C.12)**
- ❑ 3 6 – 12 months → **(Skip to C.12)**
- ❑ 4 More than 12 months

C.11d For how many years have you had stomach or abdominal pain?

_____ Record Number of Years

Other Symptoms

C.12 During the past month, have any other symptoms in addition to those we have already asked about been part of your ill-health?

- ❑ 1 Yes
- ❑ 2 No ⟶ **(Skip to C.13)**

C.12a What other symptoms have been part of your ill-health during the past month?

Please specify the symptoms using the spaces below.

1. _____
2. _____
3. _____
4. _____
5. _____

Most Bothersome Symptom

C.13 Which of the following symptoms has bothered you the most during the past month?

Please check one box that describes that symptom that bothered you most during the past month.

- ❑ 1 Fatigue, tiredness, or exhaustion
- ❑ 2 Sore throat
- ❑ 3 Tender lymph nodes or swollen glands in your neck or armpits
- ❑ 4 Unusual fatigue for at least one day after exertion
- ❑ 5 Muscle aches or pains
- ❑ 6 Joint pain
- ❑ 7 Unrefreshing sleep
- ❑ 8 Headaches
- ❑ 9 Forgetfulness or memory problems
- ❑ 10 Difficulty thinking or concentrating
- ❑ 11 Stomach or abdominal pains
- ❑ 12 Another symptom (Please specify: _____)

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10b

Multi-Site Clinical Assessment of CFS in Children and Adolescents

CDC Symptom Inventory:
For the Follow-Up Subjects

Subject ID Number: _____

Month and Year of Birth (MM/YY): _____

Start Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Complete Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

CDC Symptom Inventory

These questions are about physical symptoms that you may have experienced during the past month.

Fatigue

C.1 During the past month, have you had fatigue, tiredness, or exhaustion?

- ❑ 1 Yes
- ❑ 2 No ⟶ **(Skip to C.1f)**

C.1a During the past month, how often have you had fatigue, tiredness or exhaustion?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.1b During the past month, how bad was your fatigue, tiredness or exhaustion?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.1c Prior to this <u>past month</u>, for how long had you had fatigue, tiredness or exhaustion?

- ❑ 1 Less than 3 months → **(Skip to C.1e)**
- ❑ 2 3 – 6 months → **(Skip to C.1e)**
- ❑ 3 6 – 12 months → **(Skip to C.1e)**
- ❑ 4 More than 12 months

C.1d For how many <u>years</u> have you had fatigue, tiredness or exhaustion?

_____ Record Number of Years

C.1e Do you consider your fatigue, tiredness or exhaustion to <u>currently</u> be part of your ill-health?

- ❑ 1 Yes
- ❑ 2 No

C.1f Has fatigue, tiredness or exhaustion been a part of your ill-health <u>in the past</u>?

- ❑ 1 Yes
- ❑ 2 No

C.1g When this fatigue, tiredness, or exhaustion began, would you say that it came on all of a sudden, or slowly over time?

- ❑1 All of sudden
- ❑2 Slowly over time
- ❑6 Not applicable
- ❑8 Don't know

Sore Throat

C.2 During the past month, have you had a sore throat?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.3)**

C.2a During the past month, how often have you had a sore throat?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.2b During the past month, how bad was your sore throat?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.2c Prior to this past month, for how long had you had a sore throat?

- ❑ 1 Less than 3 months → **(Skip to C.3)**
- ❑ 2 3 – 6 months → **(Skip to C.3)**
- ❑ 3 6 – 12 months → **(Skip to C.3)**
- ❑ 4 More than 12 months

C.2d For how many years have you had a sore throat?

_____ Record Number of Years

Tender Lymph Nodes and Swollen Glands

C.3 During the past month, have you had tender lymph nodes or swollen glands in your neck or armpits?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.4)**

C.3a During the past month, how often have you had tender lymph nodes or swollen glands?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.3b During the past month, how tender were your lymph nodes or how swollen were your glands?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.3c Prior to this past month, how long had you had tender lymph nodes or swollen glands?

- ❑ 1 Less than 3 months → **(Skip to C.4)**
- ❑ 2 3 – 6 months → **(Skip to C.4)**
- ❑ 3 6 – 12 months → **(Skip to C.4)**
- ❑ 4 More than 12 months

C.3d For how many years have you had tender lymph nodes or swollen glands?

_____ Record Number of Years

Fatigue After Exertion

C.4 During the past month, have you been unusually fatigued or unwell for at least one day after exerting yourself in any way?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.5)**

C.4a During the past month, how often have you had unusual fatigue after exertion?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.4b During the past month, how bad was your unusual fatigue after exertion?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.4c Prior to this past month, for how long had you had unusual fatigue after exertion?

- ❑ 1 Less than 3 months → **(Skip to C.5)**
- ❑ 2 3 – 6 months → **(Skip to C.5)**
- ❑ 3 6 – 12 months → **(Skip to C.5)**
- ❑ 4 More than 12 months

C.4d For how many years have you had unusual fatigue after exertion?

_____ Record Number of Years

Muscle Aches and Pains

C.5 During the past month, have you had muscle aches or muscle pain?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.6)**

C.5a During the past month, how often have you had muscle aches or muscle pains?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.5b During the past month, how bad were your muscle aches or muscle pains?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.5c Prior to this past month, for how long have you had muscle aches or muscle pains?

- ❑ 1 Less than 3 months → **(Skip to C.6)**
- ❑ 2 3 – 6 months → **(Skip to C.6)**
- ❑ 3 6 – 12 months → **(Skip to C.6)**
- ❑ 4 More than 12 months

→ **C.5d For how many years have you had muscle aches or muscle pains?**

_____ Record Number of Years

Joint Pain

C.6 During the past month, have you had pain in several joints?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.7)**

C.6a During the past month, how often have you had joint pain?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.6b During the past month, how bad was the joint pain?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.6c Prior to this past month, for how long had you had joint pain?

- ❑ 1 Less than 3 months → **(Skip to C.7)**
- ❑ 2 3 – 6 months → **(Skip to C.7)**
- ❑ 3 6 – 12 months → **(Skip to C.7)**
- ❑ 4 More than 12 months

→ **C.6d For how many years have you had joint pain?**

_____ Record Number of Years

Unrefreshing Sleep

C.7 During the past month, has unrefreshing sleep been a problem for you?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.8)**

C.7a During the past month, how often have you had unrefreshing sleep?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.7b During the past month, how much of a problem was unrefreshing sleep?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.7c Prior to this past month, for how long had you had unrefreshing sleep?

- ❑ 1 Less than 3 months → **(Skip to C.8)**
- ❑ 2 3 – 6 months → **(Skip to C.8)**
- ❑ 3 6 – 12 months → **(Skip to C.8)**
- ❑ 4 More than 12 months

→ **C.7d For how many years have you had unrefreshing sleep?**

_____ Record Number of Years

Headaches

C.8 During the past month, have you had headaches?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.9)**

C.8a During the past month, how often have you had headaches?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.8b During the past month, how bad were your headaches?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.8c Prior to this past month, for how long had you had headaches?

- ❑ 1 Less than 3 months → **(Skip to C.9)**
- ❑ 2 3 – 6 months → **(Skip to C.9)**
- ❑ 3 6 – 12 months → **(Skip to C.9)**
- ❑ 4 More than 12 months

→ **C.8d For how many years have you headaches?**

_____ Record Number of Years

Memory Problems

C.9 During the past month, have you had forgetfulness or memory problems that caused you to substantially cut back on your activities?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.10)**

C.9a During the past month, how often have you had forgetfulness or memory problems?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.9b During the past month, how bad were your forgetfulness or memory problems?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.9c Prior to this past month, for how long had you forgetfulness or memory problems?

- ❑ 1 Less than 3 months → **(Skip to C.10)**
- ❑ 2 3 – 6 months → **(Skip to C.10)**
- ❑ 3 6 – 12 months → **(Skip to C.10)**
- ❑ 4 More than 12 months

→ **C.9d For how many years have you had forgetfulness or memory problems?**

_____ Record Number of Years

Concentration

C.10 During the past month, have you had difficulty with thinking or concentrating that caused you to substantially cut back on your activities?

- ❑ 1 Yes
- ❑ 2 No ⟶ **(Skip to C.11)**

C.10a During the past month, how often have you had difficulty with thinking or concentrating?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.10b During the past month, how bad was your difficulty with thinking or concentrating?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.10c Prior to this past month, for how long had you had difficulty with thinking or concentrating?

- ❑ 1 Less than 3 months ⟶ **(Skip to C.11)**
- ❑ 2 3 – 6 months ⟶ **(Skip to C.11)**
- ❑ 3 6 – 12 months ⟶ **(Skip to C.11)**
- ❑ 4 More than 12 months

C.10d For how many years have you had difficulty with thinking or concentrating?

_____ Record Number of Years

Stomach or Abdominal Pain

C.11 During the past month, have you had stomach or abdominal pain?

- ❑ 1 Yes
- ❑ 2 No → **(Skip to C.12)**

C.11a During the past month, how often have you had stomach or abdominal pain?

- ❑ 1 A little of the time
- ❑ 2 Some of the time
- ❑ 3 A good bit of the time
- ❑ 4 Most of the time
- ❑ 5 All of the time

C.11b During the past month, how bad was your stomach or abdominal pain?

- ❑ 1 Very mild
- ❑ 2 Mild
- ❑ 3 Moderate
- ❑ 4 Severe
- ❑ 5 Very severe

C.11c Prior to this past month, for how long had you had stomach or abdominal pain?

- ❑ 1 Less than 3 months → **(Skip to C.12)**
- ❑ 2 3 – 6 months → **(Skip to C.12)**
- ❑ 3 6 – 12 months → **(Skip to C.12)**
- ❑ 4 More than 12 months

C.11d For how many years have you had stomach or abdominal pain?

_____ Record Number of Years

Other Symptoms

C.12 During the past month, have any other symptoms in addition to those we have already asked about been part of your ill-health?

- ❑ 1 Yes
- ❑ 2 No ⟶ **(Skip to C.13)**

C.12a What other symptoms have been part of your ill-health during the past month?

Please specify the symptoms using the spaces below.

1. _____
2. _____
3. _____
4. _____
5. _____

Most Bothersome Symptom

C.13 Which of the following symptoms has bothered you the most during the past month?

Please check one box that describes that symptom that bothered you most during the past month.

- ❑ 1 Fatigue, tiredness, or exhaustion
- ❑ 2 Sore throat
- ❑ 3 Tender lymph nodes or swollen glands in your neck or armpits
- ❑ 4 Unusual fatigue for at least one day after exertion
- ❑ 5 Muscle aches or pains
- ❑ 6 Joint pain
- ❑ 7 Unrefreshing sleep
- ❑ 8 Headaches
- ❑ 9 Forgetfulness or memory problems
- ❑ 10 Difficulty thinking or concentrating
- ❑ 11 Stomach or abdominal pains
- ❑ 12 Another symptom (Please specify: _____)

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11

Multi-Site Clinical Assessment of CFS in Children and Adolescents

SF-36 Health Survey

Subject ID Number: _____

Start Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Complete Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

1. In general, would you say your health is:

- ❑ 1 Excellent
- ❑ 2 Very Good
- ❑ 3 Good
- ❑ 4 Fair
- ❑ 5 Poor

2. Compared <u>to one year ago</u>, how would you rate your health in general now?

- ❑ 1 Much better now than one year ago
- ❑ 2 Somewhat better now than one year ago
- ❑ 3 About the same as one year ago
- ❑ 4 Somewhat worse now than one year ago
- ❑ 5 Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

Please mark the appropriate box.

		Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a.	*Vigorous Activities*, such as running, lifting heavy objects, participating in strenuous sports.	❑1	❑2	❑3
b.	*Moderate Activities*, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	❑1	❑2	❑3
c.	Lifting or carrying groceries.	❑1	❑2	❑3
d.	Climbing *several* flights of stairs.	❑1	❑2	❑3
e.	Climbing *one* flight of stairs.	❑1	❑2	❑3
f.	Bending, kneeling, or stooping.	❑1	❑2	❑3
g.	Walking *more than a mil*e.	❑1	❑2	❑3
h.	Walking *several hundred yards.*	❑1	❑2	❑3
i.	Walking *one hundred yards.*	❑1	❑2	❑3
j.	Bathing or dressing yourself.	❑1	❑2	❑3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

Please mark the appropriate box.

		All of the Time ⬇	Most of the Time ⬇	Some of the Time ⬇	A Little of the Time ⬇	None of the Time ⬇
a.	Cut down on the *amount of time* you spent on work or other activities	❑1	❑2	❑3	❑4	❑5
b.	*Accomplished* less than you would like	❑1	❑2	❑3	❑4	❑5
c.	Were limited in the *kind* of work or other activities	❑1	❑2	❑3	❑4	❑5
d.	Had *difficulty* performing the work or other activities (for example, it took extra effort)	❑1	❑2	❑3	❑4	❑5

5. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

Please mark the appropriate box.

		All of the Time ⬇	Most of the Time ⬇	Some of the Time ⬇	A Little of the Time ⬇	None of the Time ⬇
a.	Cut down on the *amount of time* you spent on work or other activities	❑1	❑2	❑3	❑4	❑5
b.	*Accomplished* less than you would like	❑1	❑2	❑3	❑4	❑5
c.	Did work or activities *less carefully than usual*	❑1	❑2	❑3	❑4	❑5

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- ❑ 1 Not at all
- ❑ 2 Slightly
- ❑ 3 Moderately
- ❑ 4 Quite a bit
- ❑ 5 Extremely

7. How much bodily pain have you had during the past 4 weeks?

- ❑ 1 None
- ❑ 2 Very mild
- ❑ 3 Mild
- ❑ 4 Moderate
- ❑ 5 Severe
- ❑ 6 Very severe

8. During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- ❑ 1 None
- ❑ 2 A little bit
- ❑ 3 Moderately
- ❑ 4 Quite a bit
- ❑ 5 Extremely

9. **These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.**

How much of the time during the past four weeks…

Please mark the appropriate box.

		All of the Time	Most of the Time	Some of the Time	A Little Bit of the Time	None of the Time
a.	Did you feel full of life?	❑1	❑2	❑3	❑4	❑5
b.	Have you been very nervous?	❑1	❑2	❑3	❑4	❑5
c.	Have you felt so down in the dumps that nothing could cheer you up?	❑1	❑2	❑3	❑4	❑5
d.	Have you felt calm and peaceful?	❑1	❑2	❑3	❑4	❑5
e.	Did you have a lot of energy?	❑1	❑2	❑3	❑4	❑5
f.	Have you felt downhearted and depressed?	❑1	❑2	❑3	❑4	❑5
g.	Did you feel worn out?	❑1	❑2	❑3	❑4	❑5
h.	Have you been happy?	❑1	❑2	❑3	❑4	❑5
i.	Did you feel tired?	❑1	❑2	❑3	❑4	❑5

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like as visiting friends, relatives, etc.)?

- ❑ 1 All of the time
- ❑ 2 Most of the time
- ❑ 3 Some of the time
- ❑ 4 A little of the time
- ❑ 5 None of the time

11. How true or false is *each* of the following statements for you?

Please mark the appropriate box.

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick a little easier than other people.	❑ 1	❑ 2	❑ 8	❑ 3	❑ 4
b. I am as healthy as anybody I know.	❑ 1	❑ 2	❑ 8	❑ 3	❑ 4
c. I expect my health to get worse.	❑ 1	❑ 2	❑ 8	❑ 3	❑ 4
d. My health is excellent.	❑ 1	❑ 2	❑ 8	❑ 3	❑ 4

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12

Multi-Site Clinical Assessment of CFS in Children and Adolescents

Multidimensional Fatigue Inventory (MFI-20)

Subject ID Number: _____

Start Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Complete Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Multi-Dimensional Fatigue Inventory

The next questions are about how you have been feeling lately. Please place one "X" for each statement.

The more you agree with the statement, the more you should place an "X" in the direction of "yes, that is true." The more you disagree with the statement, the more you should place an X in the direction of "no, that is not true."

Take for example the statement: "I FEEL RELAXED."

If you think that this statement is entirely true, that you have been feeling relaxed lately, you would place an "X" in the box labeled "1."

yes, that is true ☒ ☐ ☐ ☐ ☐ no, that is not true
1 2 3 4 5

1. I feel fit. — yes, that is true ☐ ☐ ☐ ☐ ☐ no, that is not true (1 2 3 4 5)
2. Physically I feel only able to do a little. — yes, that is true ☐ ☐ ☐ ☐ ☐ no, that is not true (1 2 3 4 5)
3. I feel very active. — yes, that is true ☐ ☐ ☐ ☐ ☐ no, that is not true (1 2 3 4 5)
4. I feel like doing all sorts of nice things. — yes, that is true ☐ ☐ ☐ ☐ ☐ no, that is not true (1 2 3 4 5)
5. I feel tired. — yes, that is t rue ☐ ☐ ☐ ☐ ☐ no, that is not true (1 2 3 4 5)
6. I think I do a lot in a day. — yes, that is true ☐ ☐ ☐ ☐ ☐ no, that is not true (1 2 3 4 5)

7. When I am doing something, I can keep my thoughts on it.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
8. Physically I can take on a lot.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
9. I dread having to do things.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
10. I think I do very little in a day.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
11. I can concentrate well.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
12. I am rested.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
13. It takes a lot of effort to concentrate on things.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
14. Physically I feel I am in a bad condition.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
15. I have a lot of plans.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	
16. I tire easily.	yes, that is true	☐	☐	☐	☐	☐	no, that is not true
		1	2	3	4	5	

17. I get little done.	yes, that is true	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	no, that is not true
18. I don't feel like doing anything.	yes, that is true	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	no, that is not true
19. My thoughts easily wander.	yes, that is true	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	no, that is not true
20. Physically I feel I am in an excellent condition.	yes, that is true	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	no, that is not true

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Expiration date: 09/30/2023

Appendix 13

Subject ID: _____ Date (MM/DD/YY): _____/_____/_____

Selected Questions from the DePaul Pediatric Health Questionnaire (Child Version)

Please fill out this chart from left to right.

Symptoms	In this box, write the number of months you had this symptom in your **life**	Place a check in this box if you had this symptom in the **past 3 months**	*Frequency:* In the past 3 months, how often have you had this symptom? Please **circle** a number from 1-7 Hardly Ever 1 2 3 4 5 6 7 Always	*Severity:* How much has this symptom bothered you in the past 3 months? Please **circle** a number from 1-7 No Problem 1 2 3 4 5 6 7 Big Problem
1) Upset stomach			1 2 3 4 5 6 7	1 2 3 4 5 6 7
2) Ringing in ears			1 2 3 4 5 6 7	1 2 3 4 5 6 7
3) Problems remembering things			1 2 3 4 5 6 7	1 2 3 4 5 6 7
4) Difficulty paying attention for a long period of time			1 2 3 4 5 6 7	1 2 3 4 5 6 7
5) Difficulty finding the right word to say			1 2 3 4 5 6 7	1 2 3 4 5 6 7
6) Difficulty understanding things			1 2 3 4 5 6 7	1 2 3 4 5 6 7
7) Only able to focus on one thing at a time			1 2 3 4 5 6 7	1 2 3 4 5 6 7
8) Frequently losing your train of thought			1 2 3 4 5 6 7	1 2 3 4 5 6 7
9) Slowness of thought			1 2 3 4 5 6 7	1 2 3 4 5 6 7
10) Absent-mindedness or forgetfulness			1 2 3 4 5 6 7	1 2 3 4 5 6 7
11) Recent trouble with math or numbers			1 2 3 4 5 6 7	1 2 3 4 5 6 7
12) Feel unsteady on your feet, like you might fall			1 2 3 4 5 6 7	1 2 3 4 5 6 7
13) Shortness of breath or trouble catching your breath			1 2 3 4 5 6 7	1 2 3 4 5 6 7
14) Dizziness			1 2 3 4 5 6 7	1 2 3 4 5 6 7
15) Irregular heart beats			1 2 3 4 5 6 7	1 2 3 4 5 6 7
16) Some smells, foods, or chemicals make you feel sick			1 2 3 4 5 6 7	1 2 3 4 5 6 7
17) Mood changes			1 2 3 4 5 6 7	1 2 3 4 5 6 7
18) Anxiety			1 2 3 4 5 6 7	1 2 3 4 5 6 7

Subject ID: _____ Date (MM/DD/YY): _____/_____/_____

19. When you feel stress, are the following symptoms more severe?

a). Upset Stomach (vomiting, diarrhea)..... ☐ 1 Yes ☐ 2 No
b). Sweating ..... ☐ 1 Yes ☐ 2 No
c). Headaches ..... ☐ 1 Yes ☐ 2 No
d). Anxiety/Depression/Mood..... ☐ 1 Yes ☐ 2 No

e). Please list any other symptoms that become more severe when you feel stress.

_____

_____

_____

_____

_____

f). Among the symptoms you have specified above, please write down the symptom **worsen most** when you feel stress.

_____ (Please only specify **one** symptom.)

Please proceed to the next questionnaire.

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Expiration date: 09/30/2023

14 Multi-Site Clinical Assessment of CFS in Children and Adolescents

PROMIS Pediatric Instruments:
Fatigue and Pain

Subject ID Number: _____

Start Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Complete Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

PROMIS Pediatric Fatigue - Short Form 10a

Please respond to each item by marking one box per row. In the past 7 days…

Being tired made it hard for me to play or go out with my friends as much as I'd like.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I felt weak.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I got tired easily.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
Being tired made it hard for me to keep up with my schoolwork.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I had trouble finishing things because I was too tired.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I had trouble starting things because I was too tired.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I was so tired it was hard for me to pay attention.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I was too tired to do sports or exercise.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I was too tired to do things outside.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I was too tired to enjoy the things I like to do.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always

PROMIS Pediatric Pain Interference - Short Form 8a

Please respond to each item by marking one box per row. In the past 7 days...

I had trouble sleeping when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I felt angry when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I had trouble doing schoolwork when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
It was hard for me to pay attention when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
It was hard for me to run when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
It was hard for me to walk one block when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
It was hard to have fun when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
It was hard to stay standing when I had pain.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always

~ End of Questionnaire ~

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Multi-Site Clinical Assessment of CFS in Children and Adolescents

Pediatric Pain Questionnaire (PPQ)

Subject ID Number: _____

Date: _____/_____/_____
Month Day Year

Pediatric Pain Questionnaire

Understanding your pain

This questionnaire is to help us learn about your pain. We want to understand your past pain so we can diagnose and treat you.

This questionnaire and any information given in interviews will remain private. If you do not wish to answer a question, write, "do not wish to answer" in the space provided.

Please print or write clearly.

Today's date: _____

Your name: _____ Age: _____

What words would you use to describe your pain or hurt? _____

_____

_____

_____

Circle the words below that best describe your pain, or the way you feel when you are in pain.

cutting	pounding	tingling	tiring	deep
squeezing	throbbing	horrible	stabbing	burning
pulling	sickening	biting	screaming	scraping
aching	uncomfortable	cold	miserable	stretching
pricking	hot	scared	lonely	jumping
pinching	unbearable	sad	itching	grabbing
stinging	sharp	sore	flashing	pins and needles

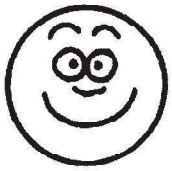
From the words you wrote or circled, which three words best describe the pain you are feeling right now?

_____

_____

_____

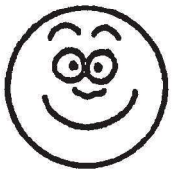
Rate **how you feel now**. If you have no pain put a mark at the end of the line by the happy face. If you have some pain, put a mark near the middle of the line. If you have a lot of pain, put a mark by the sad face.



Not hurting
No discomfort
No pain

Hurting a whole lot
Very uncomfortable
Severe pain

Rate **the worst pain you had this week**. If you had no pain this week, put a mark at the end of the line by the happy face. If the pain you had was some hurting, put a mark by the middle of the line. If the worst pain you had was a whole lot of pain, put a mark by the sad face.



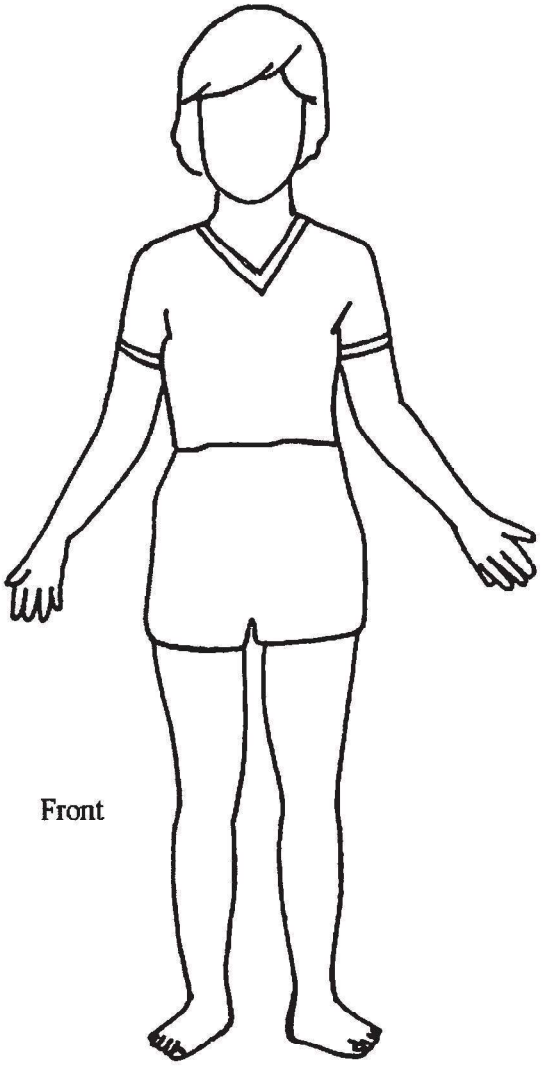
Not hurting
No discomfort
No pain

Hurting a whole lot
Very uncomfortable
Severe pain

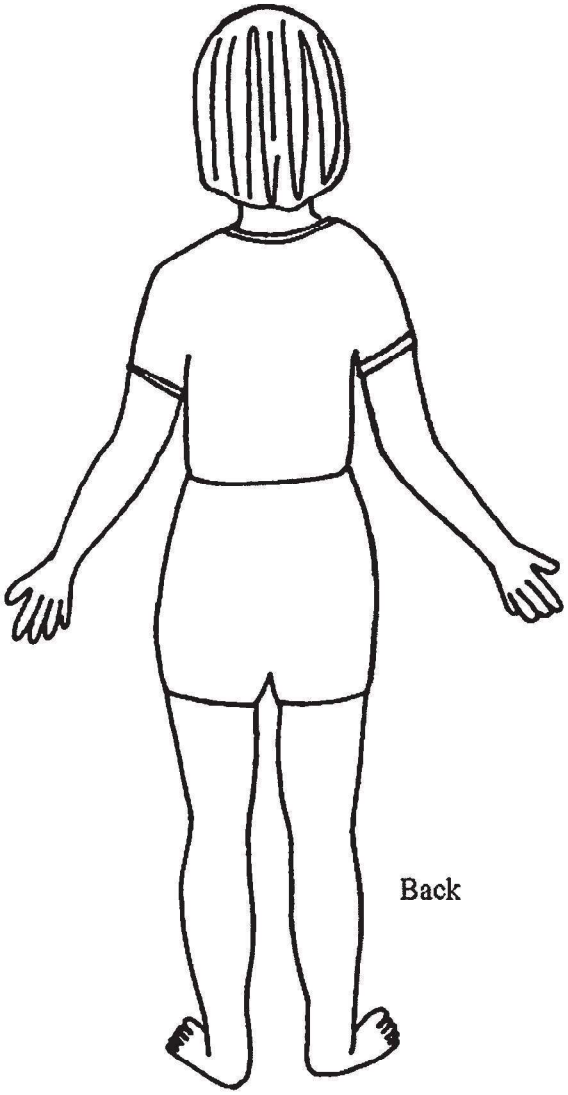
From Hockenberry MJ, Wilson D, Winkelstein ML: Wong Essentials of Pediatric Nursing, ed. 7, St. Louis, 2005, p. 1259. Used with permission. Copyright Mosby.

Pick colors that mean **no hurt**, **a little hurt**, **more hurt**, and **a lot of hurt** to you and color in the boxes. Now, using those colors, color in the body to show how you feel.

No pain No hurt	Mild pain A little hurt	Moderate pain More hurt	Severe pain A lot of hurt



Front



Back

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Expiration date: 09/30/2023

Subject ID: _____ Date (MM/DD/YY): ___/___/_____

Visual Analogue Scale (VAS)

DIRECTIONS: You are asked to place an "X" through these lines to indicate how you are feeling RIGHT NOW. For example, suppose you have not eaten since yesterday. Where would you put the "X" on the line below?

not at all hungry _____ extremely hungry

You would probably put the "X" closer to the "extremely hungry" end of the line. This is where I put it.

not at all hungry _____ extremely hungry

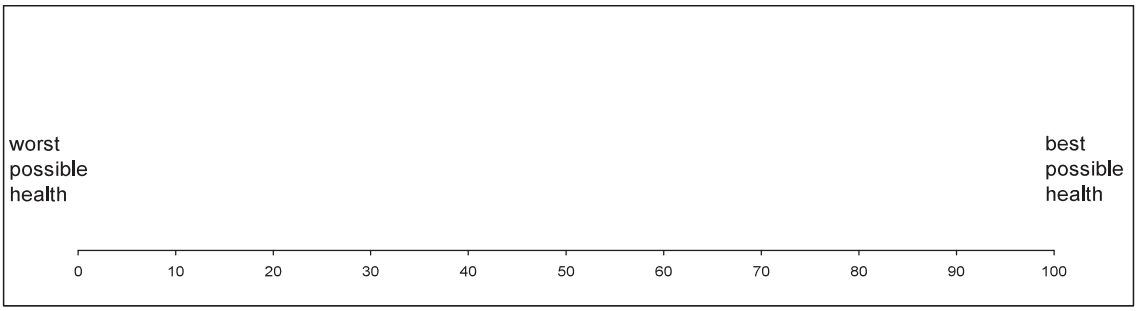
NOW PLEASE COMPLETE THE FOLLOWING ITEMS.

not at all hungry	_____	extremely hungry
not at all tired	_____	extremely tired
not at all sleepy	_____	extremely sleepy
not at all drowsy	_____	extremely drowsy
not at all fatigued	_____	extremely fatigued
not at all worn out	_____	extremely worn out
not at all energetic	_____	extremely energetic
not at all active	_____	extremely active
not at all vigorous	_____	extremely vigorous
not at all efficient	_____	extremely efficient
not at all lively	_____	extremely lively
not at all bushed	_____	totally bushed
not all exhausted	_____	totally exhausted
keeping my eyes open is no effort at all	_____	keeping my eyes open is a tremendous chore
moving my body is no effort at all	_____	moving my body is a tremendous chore
concentrating is no effort at all	_____	concentrating is a tremendous chore
carrying on a conversation is no effort at all	_____	carrying on a conversation is a tremendous chore
I have absolutely no desire to close my eyes	_____	I have a tremendous desire to close my eyes
I have absolutely no desire to lie down	_____	I have a tremendous desire to lie down

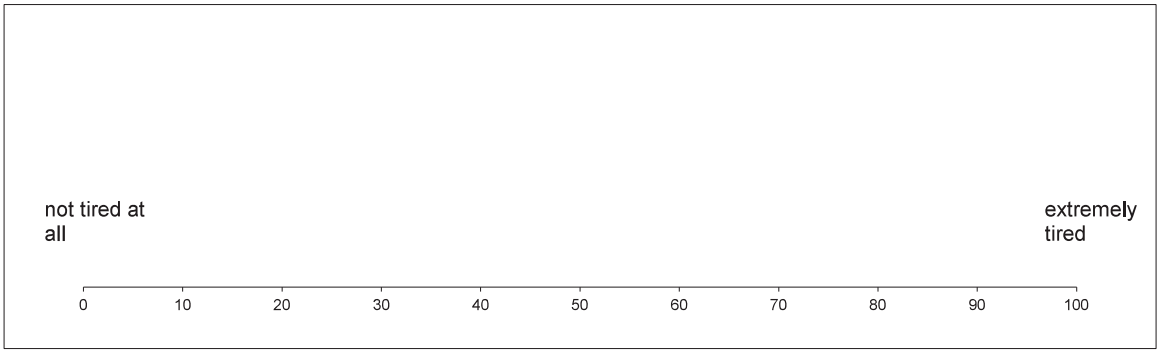
Subject ID: _____ Date (MM/DD/YY): ___/___/_____

General state of health:

1. Think about your overall health today. What number between 0 and 100 best describes your health today? Please place an "X" on the scale below.



2. Think about how tired you feel today. What number between 0 and 100 best describes how tired you feel today? Please place an "X" on the scale below.



3. Circle the number of hours per day that your child spend(s) in vertical or horizontal activity.

Hours **vertical** of 24 hours (i.e., average time with **feet on the floor**---sitting, standing or walking)

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15+

Hours **horizontal** of 24 hours (i.e., average time **with feet up**--- resting in recliner, feet up, napping, sleeping in bed)

0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15+

Subject ID: _____ Date (MM/DD/YY): ___/___/_____

Physical activity and play

Current activity level	Number of hours
How many *hours a week* does your child currently spend in physical activities/play?	
How many of the above hours are spent outdoors?	
What is his/her usual type of physical activity/play? Describe _____	

Describe your child's physical activity and play **before** he/she became ill with Chronic Fatigue/ME

Activity before he/she became ill with Chronic Fatigue/ME	Number of hours
How many hours a week did your child spend in physical activities/play before this illness?	
How many of the above hours are spent outdoors?	

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OMB Control No.: 0920-XXXX
Expiration date: 09/30/2023

Subject ID _____ Date _____

Hospital Anxiety and Depression Scale (HADS)

This questionnaire is designed to help describe how you feel. Please read each item and then place a cross in the box next to the reply that comes closest to how you have been feeling in the past week. Try to give your first reaction. This will probably be more accurate than spending a long time thinking about an answer

Please cross only one box for each question

1.1	I feel tense / wound up:	A	1.8	I feel as if I am slowed down:	D
	Most of the time	3 ☐		Nearly all of the time	3 ☐
	A lot of the time	2 ☐		Very often	2 ☐
	Occasionally	1 ☐		Sometimes	1 ☐
	Not at all	0 ☐		Not at all	0 ☐
1.2	I still enjoy things I used to:	D	1.9	I get a frightened feeling like 'butterflies' in my stomach:	A
	Definitely as much	0 ☐		Not at all	0 ☐
	Not quite as much	1 ☐		Occasionally	1 ☐
	Only a little	2 ☐		Quite often	2 ☐
	Hardly at all	3 ☐		Very often	3 ☐
1.3	I get a sort of frightened feeling as if something awful is about to happen:	A	1.10	I have lost interest in my appearance:	D
	Very definitely and quite badly	3 ☐		Definitely	3 ☐
	Not too badly	2 ☐		I don't take as much care as I should	2 ☐
	A little, but it doesn't worry me	1 ☐		I may not take quite as much care	1 ☐
	Not at all	0 ☐		I take just as much care as ever	0 ☐
1.4	I can laugh and see the funny side of things:	D	1.11	I feel restless as if I have to be on the move:	A
	As much as I ever could	0 ☐		Very much indeed	3 ☐
	Not quite as much now	1 ☐		Quite a lot	2 ☐
	Definitely not so much	2 ☐		Not very much	1 ☐
	Not at all	3 ☐		Not at all	0 ☐
1.5	Worrying thoughts go through my mind:	A	1.12	I look forward with enjoyment to things:	D
	A great deal of the time	3 ☐		As much as I ever did	0 ☐
	A lot of the time	2 ☐		Rather less than I used to	1 ☐
	From time to time	1 ☐		Definitely less than I used to	2 ☐
	Only occasionally	0 ☐		Hardly at all	3 ☐
1.6	I feel cheerful	D	1.13	I get sudden feelings of panic:	A
	Not at all	3 ☐		Very often indeed	3 ☐
	Not often	2 ☐		Quite often	2 ☐
	Sometimes	1 ☐		Not very often	1 ☐
	Most of the time	0 ☐		Not at all	0 ☐
1.7	I can sit at ease and feel relaxed:	A	1.14	I can enjoy a good book, radio or TV program:	D
	Definitely	0 ☐		Often	0 ☐
	Usually	1 ☐		Sometimes	1 ☐
	Not often	2 ☐		Not often	2 ☐
	Not at all	3 ☐		Very seldom	3 ☐

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Expiration date: 09/30/2023

Subject ID: _____ Date (MM/DD/YY): ___/___/_____

Pediatric Daytime Sleepiness Scale (PDSS)

Please answer the following questions as honestly as you can by circling one answer only:

1. How often do you fall asleep or get drowsy during class periods?

Always Frequently Sometimes Seldom Never

2. How often do you get sleepy or drowsy while doing your homework?

Always Frequently Sometimes Seldom Never

3. Are you usually alert most of the day?

Always Frequently Sometimes Seldom Never

4. How often are you ever tired and grumpy during the day?

Always Frequently Sometimes Seldom Never

5. How often do you have trouble getting out of bed in the morning?

Always Frequently Sometimes Seldom Never

6. How often do you fall back to sleep after being awakened in the morning?

Very often Often Sometimes Seldom Never

7. How often do you need someone to awaken you in the morning?

Always Frequently Sometimes Seldom Never

8. How often do you think that you need more sleep?

Very often Often Sometimes Seldom Never

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Expiration date: 09/30/2023

Subject ID: _____ Date (MM/DD/YY): ___/___/_____

Social Participation

1) What is your grade level in school? _____

Please fill in the blank with the answer that best describes your school attendance:

2) On average, I usually go to school _____.

- □1 1 day a week
- □2 2-3 days a week
- □3 4-5 days a week
- □9 N/A; I am homebound/homeschooled → **(SKIP TO QUESTION 20)**

3) When I go to school, I am usually there _____ .

- □1 The whole day (6-8 hours)
- □2 Part of the day (1-5 hours)
- □3 Sometimes the whole day and sometimes part of the day

In-School Activities

The next several questions will ask you about how often you are able to participate in a variety of in-school activities and the symptoms that affect your ability to participate in these activities.

In-School Activity	***How Often Are You Able To…?*** *Choose one answer.*			***Which Symptoms Affect Your Ability to Participate in This Activity?*** *Check all that apply…*					
	Never/ Rarely	Sometimes	Often/ Always	Overwhelming Fatigue	Joint/ Muscle Pain	Unable to Concentrate	Light-headed/ Dizzy	Headache	Other[a] (Specify)
4) Get to school on time	□1	□2	□3	□1	□1	□1	□1	□1	_____
5) Participate and keep up with the rest of your class	□1	□2	□3	□1	□1	□1	□1	□1	_____
6) Work with other students on classwork and/or group projects	□1	□2	□3	□1	□1	□1	□1	□1	_____
7) Participate in physical education class	□1	□2	□3	□1	□1	□1	□1	□1	_____
8) Go to lunch	□1	□2	□3	□1	□1	□1	□1	□1	_____
9) Other (specify): _____	□1	□2	□3	□1	□1	□1	□1	□1	_____

[a] Other symptoms may include fainting, abdominal pain, sore throat, rash, or fever.

10) How often have you had to stop or skip an in-school activity due to CFS symptoms?

□1 Never/Rarely
□2 Sometimes
□3 Often/Always

11) What kinds of in-school activities have you had to stop or skip? Please mark all that apply.

□1 Attend Class
□1 Lunch
□1 Study Hall
□1 Field Trips
□1 Assemblies
□1 In-School Clubs
□1 Driver's Ed.
□1 Other (specify _____)
□1 N/A; I haven't had to skip/stop in-school activities

12) What symptoms caused you to stop or skip these in-school activities? Please mark all that apply.

□1 Overwhelming Fatigue
□1 Joint/Muscle Pain
□1 Inability to concentrate
□1 Light-headed/dizzy
□1 Headache
□1 Other (specify_____)
□1 N/A; I haven't had to stop/skip in-school activities

After-School Activities

The next several questions will ask you about your ability to participate in a variety of after-school activities and the symptoms that affect your ability to participate in these activities.

13) How often have you had to stop or skip an after-school activity due to CFS symptoms?

□1 Never/Rarely
□2 Sometimes
□3 Often/Always

14) How often have you not been able to participate in after-school activities due to attendance requirements?

□1 Never/Rarely
□2 Sometimes
□3 Often/Always

15) What kinds of after-school activities have you not been able to participate in? Please mark all that apply.

□1 Marching band
□1 Sports team
□1 Drama/theater
□1 Academic clubs
□1 Student government/National Honor Society
□1 Mentoring/tutoring
□1 Other (specify _____)
□1 N/A; I am able to participate in after-school activities.

16) What symptoms affected your ability to participate in these after-school activities? Please mark all that apply.

□1 Overwhelming Fatigue
□1 Joint/Muscle Pain
□1 Inability to concentrate
□1 Light-headed/dizzy
□1 Headache
□1 Other (specify_____)
□1 N/A; I am able to participate in after-school activities

School Social Activities

17) How often have you had to skip school social events due to CFS symptoms?

□1 Never/Rarely
□2 Sometimes
□3 Often/Always

18) What kinds of school social events have you had to stop or skip? Please mark all that apply

□1 Athletic events
□1 School fundraisers
□1 School performances
□1 Overnight school trips
□1 Dances
□1 Special evening events (i.e. college/job fair)
□1 Other (specify _____)
□1 N/A; I haven't had to stop/skip school socials

19) What symptoms affected your ability to participate in these school social events? Please mark all that apply.

□1 Overwhelming Fatigue
□1 Joint/Muscle Pain
□1 Inability to concentrate
□1 Light-headed/dizzy
□1 Headache
□1 Other (specify_____)
□1 N/A; I haven't had to stop/skip school socials

Non-School Related Activities

The next several questions will ask you about your ability to participate in a variety of non-school related activities and the symptoms that affect your ability to participate in the activity.

20) To what degree is your social time affected by your CFS symptoms?

□1 Not at all/A little bit
□2 Moderately
□3 Quite a bit/Extremely

Subject ID: _____ Date (MM/DD/YY): ___/___/_____

Non-School Activity	*How Often…?* *Choose one answer.*			*Which Symptoms Affect Your Ability to Participate in this Activity?* *Check all that apply…*					
	Never/ Rarely	Sometimes	Often/ Always	Overwhelming Fatigue	Joint/ Muscle Pain	Unable to Concentrate	Light-headed/ Dizzy	Headache	Other[a] (Specify)
21) Do you do things outside of school with friends?	☐1	☐2	☐3	☐1	☐1	☐1	☐1	☐1	_____
22) Is your time with friends restricted due to CFS symptoms?	☐1	☐2	☐3	☐1	☐1	☐1	☐1	☐1	_____

[a] Other symptoms may include fainting, abdominal pain, sore throat, rash, or fever.

23) How often have you not been able to attend non-school related activities due to CFS symptoms?

- □1 Never/Rarely
- □2 Sometimes
- □3 Often/Always

24) What kinds of non-school related activities have you had to stop or skip? Please mark all that apply

- □1 Boy/Girl Scouts
- □1 Church activities
- □1 Camping/hiking
- □1 Concerts/theater
- □1 Family outings
- □1 Vacations
- □1 Pick-up sports games with friends
- □1 Sporting events
- □1 Social events with friends
- □1 Other (specify _____)
- □1 N/A; I haven't had to stop/skip non-school related activities

25) What symptoms affected your ability to participate in these school social events? Please mark all that apply.

- □1 Overwhelming Fatigue
- □1 Joint/Muscle Pain
- □1 Inability to concentrate
- □1 Light-headed/dizzy
- □1 Headache
- □1 Other (specify _____)
- □1 N/A; I haven't had to stop/skip non-school related activities

~ The End ~

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Subject ID: _____ Date (MM/DD/YY): ___/___/_____

Sociability

*We would like to learn more about your school attendance and participation in different activities **over the past 3 months**. For each question, please fill in the blank with the answer that fits you best.*

During the past 3 months….

1) On average, I usually went to school _____.
- □1 1 day a week
- □2 2-3 days a week
- □3 4-5 days a week
- □9 N/A; I am homebound/homeschooled → **(SKIP TO QUESTION 6)**

2) When I went to school, I was usually there _____ .
- □1 The whole day (6-8 hours)
- □2 Part of the day (1-5 hours)
- □3 Sometimes the whole day and sometimes part of the day

3) How often did you have to stop or skip an **in-school activity** due to CFS symptoms? In-school activities include class, study hall, lunch, and field trips.
- □1 Never/Rarely
- □2 Sometimes
- □3 Often/Always

4) How often did you have to stop or skip an **after-school activity** due to CFS symptoms? After-school activities include sports teams, academic clubs, marching band, and mentoring/tutoring.
- □1 Never/Rarely
- □2 Sometimes
- □3 Often/Always

5) How often did you have to skip **school social events** due to CFS symptoms? School social events include athletic events, school performances, dances, and overnight school trips.
- □1 Never/Rarely
- □2 Sometimes
- □3 Often/Always

6) How often were you not able to attend **non-school related activities** due to CFS symptoms? Non-school related activities include social events with friends, church activities, family outings, and vacations.
- □1 Never/Rarely
- □2 Sometimes
- □3 Often/Always

7) How often did you have to stop or skip hobbies, social activities, or leisure activities in order to keep up with your schoolwork?
- □1 Never/Rarely
- □2 Sometimes
- □3 Often/Always

Subject ID: _____ Date (MM/DD/YY): ___/___/_____

Now, we would like to learn more about your experiences with friends and others your age ***during the past week****.*

PROMIS Pediatric Peer Relationships - Short Form 8a

Please respond to each item by marking one box per row. In the past 7 days…

I felt accepted by other kids my age.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I was able to count on my friends.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I was able to talk about everything with my friends.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
I was good at making friends.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
My friends and I helped each other.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
Other kids wanted to be my friend.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
Other kids wanted to be with me.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always
Other kids wanted to talk to me.	☐ 0 Never	☐ 1 Almost Never	☐ 2 Sometimes	☐ 3 Often	☐ 4 Almost Always

~ End of Questionnaire ~

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21

Multi-Site Clinical Assessment of CFS in Children and Adolescents

COMPosite Autonomic Symptom Score 31 (COMPASS-31)

Subject ID Number: _____

Start Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

Complete Date: _____/_____/_____ & Time: _____am/pm
Month Day Year HH:MM

1. In the past year, have you ever felt faint, dizzy, “goofy”, or had difficulty thinking soon after standing up from a sitting or lying position?

    1 Yes

    2 No (if you marked No, please skip to question 5)

2. When standing up, how frequently do you get these feelings or symptoms?

    1 Rarely

    2 Occasionally

    3 Frequently

    4 Almost Always

3. How would you rate the severity of these feelings or symptoms?

    1 Mild

    2 Moderate

    3 Severe

4. In the past year, have these feelings or symptoms that you have experienced:

    1 Gotten much worse

    2 Gotten somewhat worse

    3 Stayed about the same

    4 Gotten somewhat better

    5 Gotten much better

    6 Completely gone

5. In the past year, have you ever noticed color changes in your skin, such as red, white, or purple?

    1 Yes

    2 No (if you marked No, please skip to question 8)

6. What parts of your body are affected by these color changes? (Check all that apply)

    1 Hands

    2 Feet

7. Are these changes in your skin color:

    1 Getting much worse
    2 Getting somewhat worse
    3 Staying about the same
    4 Getting somewhat better
    5 Getting much better
    6 Completely gone

8. In the past 5 years, what changes, if any, have occurred in your general body sweating?

    1 I sweat much more than I used to
    2 I sweat somewhat more than I used to
    3 I haven't noticed any changes in my sweating
    4 I sweat somewhat less than I used to
    5 I sweat much less than I used to

9. Do your eyes feel excessively dry?

    1 Yes
    2 No

10. Does your mouth feel excessively dry?

    1 Yes
    2 No

11. For the symptom of dry eyes or dry mouth that you have had for the longest period of time, is this symptom:

    1 I have not had any of these symptoms
    2 Getting much worse
    3 Getting somewhat worse
    4 Staying about the same
    5 Getting somewhat better
    6 Getting much better
    7 Completely gone

12. In the past year, have you noticed any changes in how quickly you get full when eating a meal?

    1 I get full a lot more quickly now than I used to

    2 I get full more quickly now than I used to

    3 I haven't noticed any change

    4 I get full less quickly now than I used to

    5 I get full a lot less quickly now than I used to

13. In the past year, have you felt excessively full or persistently full (bloated feeling) after a meal?

    1 Never

    2 Sometimes

    3 A lot of the time

14. In the past year, have you vomited after a meal?

    1 Never

    2 Sometimes

    3 A lot of the time

15. In the past year, have you had a cramping or colicky abdominal pain?

    1 Never

    2 Sometimes

    3 A lot of the time

16. In the past year, have you had any bouts of diarrhea?

    1 Yes

    2 No (if you marked No, please skip to question 20)

17. How frequently does this occur?

    1 Rarely

    2 Occasionally

    3 Frequently _____ times per month

    4 Constantly

18. How severe are these bouts of diarrhea?

1 Mild

2 Moderate

3 Severe

19. Are your bouts of diarrhea getting:

1 Much worse

2 Somewhat worse

3 Staying the same

4 Somewhat better

5 Much better

6 Completely gone

20. In the past year, have you been constipated?

1 Yes

2 No (if you marked No, please skip to question 24)

21. How frequently are you constipated?

1 Rarely

2 Occasionally

3 Frequently _____ times per month

4 Constantly

22. How severe are these episodes of constipation?

1 Mild

2 Moderate

3 Severe

23. Is your constipation getting:

1 Much worse

2 Somewhat worse

3 Staying the same

4 Somewhat better

5 Much better

6 Completely gone

24. In the past year, have you ever lost control of your bladder function?

1 Never

2 Occasionally

3 Frequently _____ times per month

4 Constantly

25. In the past year, have you had difficulty passing urine?

1 Never

2 Occasionally

3 Frequently _____ times per month

4 Constantly

26. In the past year, have you had trouble completely emptying your bladder?

1 Never

2 Occasionally

3 Frequently _____ times per month

4 Constantly

27. In the past year, without sunglasses or tinted glasses, has bright light bothered your eyes?

1 Never (if you marked Never, please skip to question 29)

2 Occasionally

3 Frequently

4 Constantly

28. How severe is this sensitivity to bright light?

1 Mild

2 Moderate

3 Severe

29. In the past year, have you had trouble focusing your eyes?

1 Never (if you marked Never, please skip to question 31)

2 Occasionally

3 Frequently

4 Constantly

30. How severe is this focusing problem?

1 Mild

2 Moderate

3 Severe

31. Is the most troublesome symptom with your eyes (i.e. sensitivity to bright light or trouble focusing) getting:

1 I have not had any of these symptoms

2 Much worse

3 Somewhat worse

4 Staying about the same

5 Somewhat better

6 Much better

7 Completely gone

THIS IS THE END OF THE SURVEY