Appendix:

Celiac Disease Questionnaire:

Demographics:

1. Age
   ____________ years

2. Gender (circle one)
   M                F

3. In what U.S. State or Territory do you live?
   __________________________

4. Race (circle one)
   Non-Hispanic white   African American   Hispanic   Asian/Pacific Islander
   Other _____ (please specify)

5. What was your highest level of schooling? (circle one)
   Grade school (1-5)     Middle School (6-8)     High School (9-12)     College (13-16)
   Graduate School (>16)

6. What is your employment status? (circle one)
   Working   In-between Jobs   Retired   Unemployed   Caretaker   Disabled

7. I am filling out this questionnaire ________ (circle one)
   At a doctor’s office   Online

Celiac Basics:

8. Do you have (circle one)
   Celiac disease   Not sure if I have celiac disease   Non-celiac gluten sensitivity (gluten-free diet treats symptoms, absence of celiac disease)
9. Did you ever have a small bowel biopsy that was consistent with celiac disease?
   Yes                         No

10. Approximately, how many years ago were you diagnosed?
    ____________

11. How long did you have symptoms prior to the diagnosis of celiac disease? (circle one)
    No symptoms        Less than 1 year        1-4 years        5-10 years         >10 years

12. What type of symptoms did you have prior to diagnosis? (Please select one)
    a) None
    b) Classic Diarrhea Predominant
    c) Non-Classical Presentation (Abdominal pain/Bloating)
    d) Routine Screening
    e) Other (Osteoporosis, Anemia, Fatigue, etc.)

13. Who do you follow with for management of your Celiac Disease? (circle all that apply)
    a) Primary Care Physician
    b) Registered Dietitian or Nutritionist
    c) Gastroenterologist
    d) Gastroenterologist that specializes in celiac disease
    e) Naturopath or a Non-traditional Medical Practitioner
    f) Other___________ (please specify)
    g) I don’t follow-up for my celiac disease care     - If you checked here, skip to Question 21
14. My physician who cares for my celiac disease is readily available if needed. (circle one)
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

15. My nutritionist or dietitian who cares for my celiac disease is readily available if needed. (circle one)
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree
   - N/A

16. Is management of your celiac disease addressed at least once per year by a physician?
   - Yes
   - No

17. I feel that my physician who cares for my celiac disease spends ample time managing my celiac disease needs. (circle one)
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

18. I feel that my physician who cares for my celiac disease is very knowledgeable about celiac disease. (circle one)
   - Strongly Agree
   - Agree
   - Neutral
   - Disagree
   - Strongly Disagree

19. How often have the emotional and psychological impacts of celiac disease on your life (including those of diet adherence) been addressed by a physician?
   - Never
   - Once
   - More than Once

20. Does your doctor check your celiac antibody levels yearly?
   - Yes
   - No
   - Unsure

21. If you are NOT followed by a nutritionist or dietitian, were you ever referred to one for dietary management?
   - Yes
   - No
   - I follow with a nutritionist or dietitian

22. Do you have yearly blood work that measures at least one of the following? (Hemoglobin, Calcium, Iron, Folate, Vitamin B12 level)
   - Yes
   - No
   - Unsure
   - Yes I have blood checked, but I am not sure what tests were done
23. Has a medical professional ever spoken to you about how celiac disease can impact your bone health?
   Yes    No    Unsure

24. Have you ever been offered or had a bone density scan?
   Yes    No    Unsure

25. Have you continued to have symptoms despite adherence to a gluten free diet?
   Yes    No    Have not been adherent    Never had symptoms

26. Have you had a repeat upper endoscopy and biopsy since diagnosis?
   Yes    No

27. Have you been offered or received your flu vaccine for this past flu season?
   I received it    I was offered but declined it    I was never offered

28. If you received the flu vaccine, who offered it to you? (circle all that apply)
   Celiac Doctor/Gastroenterologist    Primary Care Physician    Employer
   I went to the pharmacy on my own for the vaccine    Other________

29. Have you been offered or received the Pneumovax (pneumonia) vaccine?
   I received it    I was offered but declined it    I was never offered    Unsure

30. Are you a member of a celiac support group?
   Yes    No

31. If so (if you answered yes to Q29), have you been an active member of the group in the past year (attended meetings, functions etc)?
   Yes    No

32. Do you go to a specialized celiac disease center for your care?
   Yes    No
Patient Satisfaction:

33. I am satisfied with the physician that I see for my primary care needs (circle one)
   Strongly Agree     Agree     Neutral     Disagree     Strongly Disagree     N/A

34. I am satisfied with my Gastroenterologist (GI doctor) (circle one)
   Strongly Agree     Agree     Neutral     Disagree     Strongly Disagree     N/A

35. I am satisfied with my Celiac Specialist Physician (circle one)
   Strongly Agree     Agree     Neutral     Disagree     Strongly Disagree     N/A

36. I am satisfied with my Dietitian or Nutritionist I see regularly for my celiac disease care
   Strongly Agree     Agree     Neutral     Disagree     Strongly Disagree     N/A

37. I am satisfied with my doctor who diagnosed my celiac disease
   Strongly Agree     Agree     Neutral     Disagree     Strongly Disagree

38. I am satisfied with my celiac disease care
   Strongly Agree     Agree     Neutral     Disagree     Strongly Disagree

Celiac Quality of Life Questionnaire:

Please consider each of these questions as a reflection of your life over the past month and circle the one answer that most applies:

39. I feel limited by this disease
   Not at all     Slightly     Moderately     Quite a bit     A great deal

40. I feel worried that I will suffer from this disease
   Not at all     Slightly     Moderately     Quite a bit     A great deal

41. I feel concerned that this disease will cause other health problems
   Not at all     Slightly     Moderately     Quite a bit     A great deal

42. I feel worried about my increased risk of cancer from this disease
<table>
<thead>
<tr>
<th>43. I feel socially stigmatized for having this disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>44. I feel like I’m limited in eating meals with coworkers</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>45. I feel like I am not able to have special foods like birthday cake and pizza</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>46. I feel that the diet is sufficient treatment for my disease</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>47. I feel that there are NOT enough choices for my treatment</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>48. I feel depressed because of my disease</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>49. I feel frightened by having this disease</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>50. I feel like I don’t know enough about the disease</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>51. I feel overwhelmed about having this disease</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>52. I have trouble socializing because of my disease</td>
</tr>
<tr>
<td>Not at all           Slightly          Moderately          Quite a bit          A great deal</td>
</tr>
<tr>
<td>53. I find it difficult to travel or take long trips because of my disease</td>
</tr>
</tbody>
</table>
Not at all  Slightly  Moderately  Quite a bit  A great deal

54. I feel like I cannot live a normal life because of my disease
   Not at all  Slightly  Moderately  Quite a bit  A great deal

55. I feel afraid to eat out because my food may be contaminated
   Not at all  Slightly  Moderately  Quite a bit  A great deal

56. I feel worried about the increased risk of one of my family members having celiac disease
   Not at all  Slightly  Moderately  Quite a bit  A great deal

57. I feel like I think about food all the time
   Not at all  Slightly  Moderately  Quite a bit  A great deal

58. I feel concerned that my long-term health will be affected
   Not at all  Slightly  Moderately  Quite a bit  A great deal

**Celiac Symptom Severity:**

59. I feel that my symptoms are: (circle one)
   Severe  Moderate  Mild  Minimal  Absent

**Celiac Dietary Adherence:**

60. Have you been bothered by low energy levels during the past 4 weeks?
   None of the time  A little of the time  Some of the time  Most of the time  All of the time

61. Have you been bothered by headaches during the past 4 weeks?
   None of the time  A little of the time  Some of the time  Most of the time  All of the time

62. I am able to follow a gluten-free diet when dining outside my home
   Strongly agree  Somewhat agree  Neither agree  Somewhat disagree  Strongly disagree
63. Before I do something I carefully consider the consequences

   Strongly agree  Somewhat agree  Neither agree nor disagree  Somewhat disagree  Strongly disagree

64. I do not consider myself a failure

   Strongly agree  Somewhat agree  Neither agree nor disagree  Somewhat disagree  Strongly disagree

65. How important to your health are accidental gluten exposures?

   Very Important  Somewhat important  Neutral/Unsure  A little important  Not at all

66. Over the past 4 weeks, how many times have you eaten foods containing gluten on purpose?

   0 (never)  1-2  3-5  6-10  >10