

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

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

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
nor disagree 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