

## Questionnaire

The purpose of this survey is to assess stress experienced by parents of children diagnosed with Eosinophilic Esophagitis.

### **Demographic Information:**

1. Person completing the questionnaire:

- a. Mother
- b. Father
- c. Both parents
- d. Other: \_\_\_\_\_

2. How old is your child? \_\_\_\_\_

3. Parental Marital Status:

- a. Married
- b. Single
- c. Never Married
- d. Divorced
- e. Other: \_\_\_\_\_

4. Child lives with:

- a. Mother
- b. Father
- c. Both parents
- d. Other: \_\_\_\_\_

5. Mother's Level of Education:

- a. Some high school
- b. Graduated high school or GED diploma
- c. Some college
- d. Associate's degree
- e. Bachelor's degree
- f. Some graduate school
- g. Master's degree
- h. Doctoral degree
- i. Technical School

6. Father's Level of Education:

- a. Some high school
- b. Graduated high school or GED diploma

- c. Some college
- d. Associate's degree
- e. Bachelor's degree
- f. Some graduate school
- g. Master's degree
- h. Doctoral degree
- i. Technical School

7. Mother's Occupation: \_\_\_\_\_

8. Father's Occupation: \_\_\_\_\_

9. Mother's age: \_\_\_\_\_

10. Father's age: \_\_\_\_\_

11. Child's Sex:

- a. Female
- b. Male

12. Child's Ethnicity:

- a. Caucasian
- b. Hispanic or Latino
- c. African American or Black
- d. Asian
- e. Native Hawaiian or Other Pacific Islander
- f. American Indian
- g. Other: \_\_\_\_\_

**Please answer these questions to the best of your memory.**

13. How long did your child experience EoE symptoms before a gastroenterologist diagnosed your child with EoE?

- a. 0-6 months
- b. 6-12 months
- c. 12-24 months
- d. 24-48 months
- e. Over 48 months

14. How long has your child had the diagnosis of EoE?

- a. 0-6 months
- b. 6-12 months
- c. 12-24 months

- d. 24-48 months
- e. Over 48 months

15. How stressful was it for your child to experience these symptoms without a formal diagnosis of EoE?

1=not at all, 2= somewhat, 3= moderate, 4= significant, 5= severe

1            2            3            4            5

16. Does your child have siblings?

- a. Yes
- b. No

If yes, please list siblings age and gender: \_\_\_\_\_

\_\_\_\_\_

17. Have you noticed a change in sibling's behavior since your child's EoE diagnosis? (please answer for each sibling)

Child 1-Age\_\_\_:

- a. Jealousy
- b. Regression in certain areas
- c. Acted out for attention
- d. Decline in school grades
- e. I do not notice a change in behavior
- f. Other: \_\_\_\_\_

Child 2-Age\_\_\_:

- a. Jealousy
- b. Regression in certain areas
- c. Acted out for attention
- d. Decline in school grades
- e. I do not notice a change in behavior
- f. Other: \_\_\_\_\_

Child 3-Age\_\_\_:

- a. Jealousy
- b. Regression in certain areas
- c. Acted out for attention
- d. Decline in school grades
- e. I do not notice a change in behavior

Other: \_\_\_\_\_

18. As a result of your child's EoE, have you experienced any of these stressors (please check all that apply):

- a. Loss of job due to amount and/or frequency of your child's medical appointments
- b. Lack of consistent transportation to and from medical appointments
- c. Financial strain to purchase food required in patient's diet
- d. No insurance
- e. Inconsistent insurance
- f. Financial strain to pay bills (electric, telephone etc...)
- g. Financial strain to pay for your child's EoE medications
- h. I have not experienced any of these stressors

19. As a result of your child's EoE, have you had difficulty accessing resources? (ex. Medicaid, Temporary Aid to Needy Families (TANF), formula, food stamps)

- a. Yes
- b. No

If yes, please explain: \_\_\_\_\_  
\_\_\_\_\_

20. As a result of EoE, is your child experiencing any difficulties in school (please circle all that apply):

- a. Difficulty with peer relationships
- b. Cannot participate in classroom activities (ex. Birthday parties, seasonal parties)
- c. Tardiness
- d. Absences
- e. Falling behind grade level in any subject
- f. Issue getting educational plans if parent requested (ex. 504 plan or IEP)
- g. Issues with school cafeteria and your child being able to eat food served by school cafeteria
- h. Child has to eat at a different table than his peers due to food allergies
- i. Other: \_\_\_\_\_

21. How stressful do you find the following activities since your child's EoE diagnosis:

1=not at all, 2= somewhat, 3= moderate, 4= significant, 5= severe

a. Family structure at meal times (ex. Family used to eat together and this has changed)

1                      2                      3                      4                      5

b. Buying and cooking separate foods/meals for your child to fit into dietary requirements

1                      2                      3                      4                      5

c. Financial strain due to medical appointments (ex. Missing work due to medical appointments)

1                      2                      3                      4                      5

d. Financial strain due to cost of buying food that fits dietary requirements

1                      2                      3                      4                      5

e. Financial strain due to cost of your child's EoE medications

1                      2                      3                      4                      5

f. Changes in sibling's behavior

1                      2                      3                      4                      5

g. Other: \_\_\_\_\_  
1                      2                      3                      4                      5

i. No stress

22. Has your child in the past or is currently attending therapy for any of these conditions:

- a. Anxiety
- b. Depression

- c. Feeling different from family members due to EoE diagnosis
- d. Other: \_\_\_\_\_
- e. No therapy

23. Have you, significant other or family unit in the past or currently attending therapy for any of these conditions:

- a. Anxiety
- b. Depression
- c. Coping with your child's diagnosis of EoE
- d. Other: \_\_\_\_\_
- e. No therapy

**The next set of questions asks you to rate your response on a scale of 1-5. Please circle the appropriate number as 1=not at all, 2= somewhat, 3= moderate, 4= significant, 5= severe.**

24. What is your current stress level in response to your child's EoE:

1                      2                      3                      4                      5

25. How much do you feel your current stress level has worsened by your child's EoE?

1                      2                      3                      4                      5

26. How much do you feel your current stress level has improved by your child's diagnosis of EoE?

1                      2                      3                      4                      5

27. Do you feel your child's EoE has positively affected your marital relationship?

1                      2                      3                      4                      5

27. Do you feel your child's EoE has negatively affected your marital relationship?

1                      2                      3                      4                      5

28. How much control do you feel your child's EoE has on your life?

1                      2                      3                      4                      5

29. My child's EoE has affected my social life:

1                      2                      3                      4                      5

APFED question:

How many APFED conferences have you attended?

- a. 0-1
- b. 2-3
- c. 4-5
- d. More than 5