Please complete this form anytime there is a change in your child’s health, medical, or nutrition status. Once completed, please return the ENTIRE form in the enclosed envelope.

The following answers will be used for research purposes only and will be strictly confidential.

**PATIENT INFORMATION**

<table>
<thead>
<tr>
<th>SUBJECT ID: _______________________</th>
<th>BIRTH DATE: _______________________</th>
</tr>
</thead>
<tbody>
<tr>
<td>WHO IS FILLING OUT THE FORM?: SELF □ PARENT □</td>
<td></td>
</tr>
</tbody>
</table>

When returning this form, please answer the following 3 questions. Provide one answer per question.

Please tell us your child’s compliance with the **current** dietary treatment:

- □ Never complies
- □ Sometimes
- □ Often
- □ Most of the time
- □ Always
- □ NA, not on dietary treatment

Please tell us your child’s compliance with taking the **current** prescribed Formula/Medical Food:

- □ Never complies
- □ Sometimes
- □ Often
- □ Most of the time
- □ Always
- □ NA, not on Formula/Medical food

Please tell us your child’s compliance with taking their **current** Kuvan™ prescription?

- □ Never complies
- □ Sometimes
- □ Often
- □ Most of the time
- □ Always
- □ NA, not on Kuvan™

Please check any boxes below that apply to your child, then fill out the related section in the form. Only check a box if that thing has changed since the last health update. Only fill out the sections that apply to the boxes you checked. **If you skip a box because there was no change, then you should also skip that section.**

1. □ My child’s Kuvan™ prescription has changed (Go to Section A, page 2)
2. □ My child’s Diet prescription has changed (Go to Section B, page 3)
3. □ My child’s Medical food (Formula) prescription has changed (Go to Section C, page 4)
4. □ My child’s general eating habits or food intake has changed (Go to Section D, page 5)
5. □ My child’s health status has changed (Go to Section E, page 5)

6. □ One or more of my child’s other prescription medicines has changed (Go to Section F, page 6)

7. □ One or more of my child’s regular over-the-counter (OTC) medicines or supplements has changed (Go to Section G, page 6)

8. □ My child’s physical activity level has changed (Go to Section H, page 7)

9. □ One or more of my child’s healthcare providers (eg: Doctor, Dietician, specialist, etc) has changed (Go to Section I, page 7)

SECTION A: My child’s Kuvan™ prescription has changed

1. Which change in prescription Kuvan™ occurred?
   □ My child stopped taking Kuvan™
   □ My child started taking Kuvan™
   □ My child’s current Kuvan™ dose increased
   □ My child’s current Kuvan™ dose decreased

2. Please give your child’s new prescribed Kuvan™ dose (g/Kg)__________________, tablet amount (total # of tablets/day)__________________, and pattern (on empty stomach, with food, with juice)__________________________.

3. Date of change for your child’s Kuvan™ prescription (month/day/year): _________________________

4. Who decided to make this change to your child’s Kuvan™ prescription?
   □ Nurse practitioner
   □ Physician’s assistant (PA)
   □ Primary care/Family doctor
   □ Physician specialist (describe type of specialist)__________________
   □ Parent or Self
   □ Dietician
   □ Other (please describe)__________________

5. Please tell us the reason why the prescription medicine was changed___________________________

6. What happened to your child’s compliance in taking Kuvan™ when his/her prescription changed?
   □ Taking the Kuvan™ prescription became easier
   □ Taking the Kuvan™ prescription became more difficult
   □ There was no change in my child’s compliance
   □ NA: not taking Kuvan™ or just started Kuvan™
SECTION B: My child’s Diet (PHE or Protein) prescription has changed

1. Which change in your child’s prescribed daily PHE or protein occurred?
   - [ ] My child’s daily PHE/Protein prescription increased
   - [ ] My child’s daily PHE/Protein prescription decreased
   - [ ] My child has stopped the PHE/Protein diet prescription
   - [ ] My child has started or restarted a PHE/Protein diet prescription

2. Date of diet prescription change (month/day/year): _________________________

   Please give the new daily PHE, Protein, or Exchange prescription (example – 15 exchanges, 200 mg PHE, or 13 grams of protein per day): ______________________________________________________________

3. Who decided to make this change to your child’s diet prescription?
   - [ ] Nurse practitioner
   - [ ] Physician’s assistant (PA)
   - [ ] Primary care/Family doctor
   - [ ] Physician specialist (describe type of specialist) ________________
   - [ ] Parent or Self
   - [ ] Dietician
   - [ ] Other (please describe) ________________________

4. Please tell us why the amount of PHE, Protein, or Exchanges was changed _____________________________________________________________

5. What happened to your child’s dietary compliance when his/her PHE or protein prescription was changed?
   - [ ] Following the diet prescription became easier for my child
   - [ ] Following the diet prescription became more difficult for my child
   - [ ] There was no change in my child following the diet prescription
   - [ ] NA: My child is not on a diet prescription, or my child has just started diet prescription

6. If your child’s prescribed PHE or protein increased or decreased, which foods is he/she eating more or less of? Skip any foods that have not changed for him/her.

<table>
<thead>
<tr>
<th>Fruits</th>
<th>Eating more</th>
<th>Eating less</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vegetables</td>
<td>Eating more</td>
<td>Eating less</td>
</tr>
<tr>
<td>Juices</td>
<td>Eating more</td>
<td>Eating less</td>
</tr>
<tr>
<td>Eggs or egg products</td>
<td>Eating more</td>
<td>Eating less</td>
</tr>
<tr>
<td>Milk products (not cheese)</td>
<td>Eating more</td>
<td>Eating less</td>
</tr>
<tr>
<td>Cheese products</td>
<td>Eating more</td>
<td>Eating less</td>
</tr>
</tbody>
</table>
**Legumes (beans, nuts, soy)** | Eating more □ | Eating less □ |
---|---|---|
**Meat** | Eating more □ | Eating less □ |
**Grains (bread, cereal, rice, pasta)** | Eating more □ | Eating less □ |
**Nutrient bars** | Eating more □ | Eating less □ |
**Nutrient drinks (Boost, Ensure)** | Eating more □ | Eating less □ |
**Special low protein food** | Eating more □ | Eating less □ |
**Chips (potato/corn) and crackers** | Eating more □ | Eating less □ |
**Sweet pastries (e.g., Donuts, cookies)** | Eating more □ | Eating less □ |
**Sweet drinks (e.g., Soda, fruit punch, sweet tea)** | Eating more □ | Eating less □ |
**Unsweetened drinks (e.g., water, sugarless tea, diet soda)** | Eating more □ | Eating less □ |
**Milk-based Candy Bars (e.g., Chocolate, caramel, nougat)** | Eating more □ | Eating less □ |
**Other Candy (e.g., Hard candies, chewy candy)** | Eating more □ | Eating less □ |
**Other (describe)______________________________** | Eating more □ | Eating less □ |

### SECTION C: My child’s Medical Food (Formula) prescription has changed

1. Which change in your prescription Formula/Medical food occurred?
   - [ ] My child’s daily Medical food (Formula) prescription increased
   - [ ] My child’s daily Medical food (Formula) prescription decreased
   - [ ] My child has stopped his/her Medical food (Formula)
   - [ ] My child has started or restarted Medical food (Formula)
   - [ ] The type or brand of Medical food (Formula) that my child takes has changed

   Please give your child’s new Formula Prescription (example – Phenylfree 180 grams, Koolaid 2 TB, 20 oz water):
   ________________________________
   ________________________________

2. Date that your child’s prescription Medical food (Formula) changed (month/day/year): _____________

3. Who decided to make this change to your child’s Medical food (Formula) prescription?
   - [ ] Nurse practitioner
   - [ ] Physician’s assistant (PA)
   - [ ] Primary care/Family doctor
   - [ ] Physician specialist (describe type of specialist)________________________
   - [ ] Parent or Self
   - [ ] Dietician
   - [ ] Other (please describe)________________________

4. Please tell us why the amount of Medical food (Formula) was changed________________________
   ________________________________
5. What happened to your child’s compliance in taking the Medical food (Formula) when his/her prescription was changed?

- Taking the Medical food (Formula) prescription became easier for my child
- Taking the Medical food (Formula) prescription became more difficult for my child
- There was no change in my child’s Medical food (Formula) compliance
- NA: not on a Medical food (Formula) prescription, or just started on Medical food (Formula)

SECTION D: My child’s general eating habits or food intake has changed

Check only what applies. Skip anything that does not apply to your child or that has not changed:

- Popular diet plan (for example: Atkins, Dean Ornish, Zone, Nutrisystem, WeightWatchers, DASH)
  What is the name of your diet plan?________________  Started □  Stopped □  Date______

- Vegetarian diet  Started □  Stopped □  Date____________
- Vegan diet   Started □  Stopped □  Date____________
- Calorie intake  Increased □  Decreased □  Date____________
- Cholesterol intake  Increased □  Decreased □  Date____________
- Fat intake  Increased □  Decreased □  Date____________
- Sodium (salt) intake  Increased □  Decreased □  Date____________
- Carbohydrate intake  Increased □  Decreased □  Date____________
- Protein intake  Increased □  Decreased □  Date____________
- Other changes in your child’s diet or food intake not related to Phe____________________________       Date____________

SECTION E: My child’s health status has changed

1. Was your child diagnosed with a new medical condition, or experienced the onset of a new medical condition?  Yes □  No □
   If yes, please describe the new medical condition:_____________________________________________
   _______________________________________________________________________________________
   Date of onset or diagnosis for medical condition: ________/______/_____
   Month            Day            Year

2. Did a recent medical condition get better or improve?     Yes □  No □
   If yes, please describe the medical condition:_________________________________________________
   _______________________________________________________________________________________
   Date the medical condition got better (or date you were told the condition was better):  _____/_____/_____
SECTION F: One or more of my child’s prescription medicines has changed (This does not apply to Kuvan™)

1. Which change in your child’s prescription medicines has occurred?
   - [ ] My child stopped taking a medicine
   - [ ] My child started taking a new medicine
   - [ ] My child’s current medicine dose increased
   - [ ] My child’s current medicine dose decreased

2. Please give the name of the prescription medicine ________________________________,
   New prescribed dose (g, mg, µg)___________________, How often (eg: # of times/day)______________.

3. Who decided to make this change to your child’s prescription medicine?
   - [ ] Nurse practitioner
   - [ ] Physician’s assistant (PA)
   - [ ] Primary care/Family doctor
   - [ ] Physician specialist (describe type of specialist)_________________
   - [ ] Parent or Self
   - [ ] Other (please describe)____________________

4. Please tell us why the prescription medicine was changed__________________________
   ___________________________________________________________________________
   ___________________________________________________________________________

SECTION G: One or more of my child’s regular over-the-counter (OTC) medicines or supplements has changed

1. Which change in your child’s OTC medicines or supplements occurred?
   - [ ] Stopped taking a regular supplement or OTC
   - [ ] Started regularly taking a supplement or OTC
   - [ ] Increased the dose of a supplement or OTC
   - [ ] Decreased the dose of a supplement or OTC

2. Please give the name of the OTC medicine or of the supplement__________________________,
   New dose (g, mg, IU, ml, tsps, etc.)_______________________, How often (eg: # of times/day)______________.

3. Who decided to make this change in supplements or OTC medicine?
   - [ ] Primary care provider/Family doctor
   - [ ] Physician specialist (describe type of specialist)_________________
   - [ ] Parent or Self
   - [ ] Friend, relative, or acquaintance
   - [ ] Dietician
   - [ ] Holistic or complementary health professional (describe type)_________________
   - [ ] Other (please describe)____________________

4. Please tell us why there was a change in your child’s regular supplements or OTC medicines__________
   ___________________________________________________________________________
   ___________________________________________________________________________
SECTION H: My child’s level of physical activity has changed

1. My child’s level of physical activity has:  
   - [ ] Increased  
   - [ ] Decreased

2. My child’s new physical activity status is:
   - [ ] Almost no physical activity  
   - [ ] Mild/Light physical activity  
   - [ ] Moderate physical activity  
   - [ ] Very physically active  
   - [ ] Extremely physically active

SECTION I: One or more of my child’s healthcare providers (ie: Doctor, Dietitian, specialist) has changed

1. What was the change that occurred?
   - [ ] My child started seeing a specialist, doctor, or health professional that he/she was not seeing before
     a. Which of the following healthcare professionals did your child start seeing?
        - [ ] Primary care provider/Family doctor  
        - [ ] Physician specialist (describe type of specialist)______________________  
        - [ ] Dietician  
        - [ ] Holistic or complementary health professional (describe type)______________________  
        - [ ] Other (please describe)______________________
     b. Date of change (month/year)__________________________

   - [ ] My child stopped seeing a certain Specialist/Doctor/Healthcare professional  
     a. Which of the following healthcare professionals did your child stop seeing?
        - [ ] Primary care provider/Family doctor  
        - [ ] Physician specialist (describe type of specialist)______________________  
        - [ ] Dietician  
        - [ ] Holistic or complementary health professional (describe type)______________________  
        - [ ] Other (please describe)______________________
     b. Date of change (month/year)__________________________

2. Please tell us why this change occurred (for example: no longer needs treatment, switched to new dietician, moved to new location, etc):____________________________________________________
   ____________________________________________________________________