Subject Medical Update Form

Please complete this form anytime there is a change in your 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

SUBJECT ID: _______________________ BIRTH DATE: _______________________

WHO IS FILLING OUT THE FORM?: SELF ☐ PARENT ☐

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

Please tell us your compliance with the current dietary treatment:
☐ Never complies ☐ Sometimes ☐ Often ☐ Most of the time ☐ Always
☐ NA, not on dietary treatment

Please tell us your 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 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 you, 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 Kuvan™ prescription has changed (Go to Section A, page 2)

2. ☐ My Diet prescription has changed (Go to Section B, page 3)

3. ☐ My Medical food (Formula) prescription has changed (Go to Section C, page 4)

4. ☐ My general eating habits or food intake has changed (Go to Section D, page 5)
5. [ ] My health status has changed (Go to Section E, page 5)

6. [ ] One or more of my other prescription medicines has changed (Go to Section F, page 6)

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

8. [ ] My physical activity level has changed (Go to Section H, page 7)

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

SECTION A: My Kuvan™ prescription has changed

1. Which change in prescription Kuvan™ occurred?
   - [ ] I stopped taking Kuvan™
   - [ ] I started taking Kuvan™
   - [ ] My current Kuvan™ dose increased
   - [ ] My current Kuvan™ dose decreased

2. Please give your 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 Kuvan™ prescription (month/day/year): _________________________

4. Who decided to make this change to your 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 compliance in taking Kuvan™ when the prescription changed?
   - [ ] Taking the Kuvan™ prescription became easier
   - [ ] Taking the Kuvan™ prescription became more difficult
   - [ ] There was no change in my compliance
   - [ ] NA: not taking Kuvan™ or just started Kuvan™

7. [ ] My nutrition has changed (Go to Section J, page 7)
SECTION B: My Diet (PHE or Protein) prescription has changed

1. Which change in your prescribed daily PHE or protein occurred?
   - [ ] My daily PHE/Protein prescription increased
   - [ ] My daily PHE/Protein prescription decreased
   - [ ] I stopped the PHE/Protein diet prescription
   - [ ] I have 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 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 dietary compliance when your PHE or protein prescription was changed?
   - [ ] Following the diet prescription became easier
   - [ ] Following the diet prescription became more difficult
   - [ ] There was no change in following the diet prescription
   - [ ] NA: not on a diet prescription, or just started diet prescription

6. If your prescribed PHE or protein increased or decreased, which foods are you eating more or less of? Skip any foods that have not changed for you.

<table>
<thead>
<tr>
<th>Food Type</th>
<th>Eating more</th>
<th>Eating less</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fruits</td>
<td></td>
<td></td>
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<tr>
<td>Vegetables</td>
<td></td>
<td></td>
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<tr>
<td>Juices</td>
<td></td>
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<tr>
<td>Eggs or egg products</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Milk products (not cheese)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cheese products</td>
<td></td>
<td></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 (eg: Donuts, cookies) Eating more □ Eating less □
Sweet drinks (eg: Soda, fruit punch, sweet tea) Eating more □ Eating less □
Unsweetened drinks (eg:water, sugarless tea, diet soda) Eating more □ Eating less □
Milk-based Candy Bars (eg: Chocolate, caramel, nougat) Eating more □ Eating less □
Other Candy (eg: Hard candies, chewy candy) Eating more □ Eating less □
Other (describe)______________________________ Eating more □ Eating less □

SECTION C: My Medical Food (Formula) prescription has changed

1. Which change in your prescription Formula/Medical food occurred?
   - [ ] My daily Medical food (Formula) prescription increased
   - [ ] My daily Medical food (Formula) prescription decreased
   - [ ] I have stopped my Medical food (Formula)
   - [ ] I have started or restarted Medical food (Formula)
   - [ ] The type or brand of Medical food (Formula) that I take has changed

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

2. Date that your prescription Medical food (Formula) changed (month/day/year): ____________________

3. Who decided to make this change to your 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 compliance in taking the Medical food (Formula) when your prescription was changed?

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

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

Check only what applies. Skip anything that does not apply to you 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 ☐
- Cholesterol intake  Increased ☐  Decreased ☐
- Fat intake  Increased ☐  Decreased ☐
- Sodium (salt) intake  Increased ☐  Decreased ☐
- Carbohydrate intake  Increased ☐  Decreased ☐
- Protein intake  Increased ☐  Decreased ☐
- Other changes in your diet or food intake not related to Phe________________________________________  Date______________

SECTION E: My health status has changed

1. Were you 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):  _____/_____/_____
   Month        Day           Year
SECTION F: One or more of my prescription medicines has changed (This does not apply to Kuvan™)

1. Which change in your prescription medicines has occurred?
   - [ ] I stopped taking a medicine
   - [ ] I started taking a new medicine
   - [ ] My current medicine dose increased
   - [ ] My 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 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 regular over-the-counter (OTC) medicines or supplements has changed

1. Which change in your 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 supplements or OTC medicines__________________
   ____________________________________________________________________________
SECTION H: My level of physical activity has changed
1. My level of physical activity has: Increased ☐ Decreased ☐

2. My 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 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):____________________________________________________
__________________________________________________________________________________