PKU and its effect on your and your child’s everyday life - Parents -

Before filling in this questionnaire, please write today’s date

/__/__/ /__/__/ /__/__/__/

day month year

You are:  □ The father
□ The mother

If you have more than one PKU child, please complete one questionnaire per PKU child.

• This questionnaire was designed with the help of parents of children with Phenylketonuria (PKU). It was developed in order to understand the effect of PKU and its treatment on your everyday life as a parent and on your child’s life.

• By supplement or amino acid mixture, we mean the product or liquid (for example milk, powder) prescribed to your child by their doctor.

• Unless otherwise instructed, please think about the past 7 days when answering these questions.

• Please fill out this questionnaire in a quiet area and, if possible, by yourself.

• If you do not know how to answer, please choose the response that best applies to you or your child.

• Please tell us about your experience with PKU; there are no “right” or “wrong” answers.

• Please take all the time you need.

Thank you very much for your participation.

The information in this questionnaire will remain strictly confidential and anonymous.
YOUR CHILD’S HEALTH

Following are some things that children with PKU may experience. For each sentence, please tick the box that best applied to your child.

1. In the past 7 days, compared to others my child’s age, I think my child’s health in general was:
   - Poor
   - Fair
   - Good
   - Very good
   - Excellent

   □ 0 □ 1 □ 2 □ 3 □ 4

2a. In the past 7 days, my child held their head as if it hurt or said their head hurt
   - Never
   - A little of the time
   - Sometimes
   - Often
   - Very often

   □ 0 □ 1 □ 2 □ 3 □ 4

   2b. If your child had this, do you think it was related to PKU?
   - Yes
   - No
   - I don’t know

   □ 0 □ 1 □ 2

3a. In the past 7 days, my child held their stomach as if it hurt or said their stomach hurt
   - Never
   - A little of the time
   - Sometimes
   - Often
   - Very often

   □ 0 □ 1 □ 2 □ 3 □ 4

   3b. If your child had this, do you think it was related to PKU?
   - Yes
   - No
   - I don’t know

   □ 0 □ 1 □ 2

4a. In the past 7 days, my child seemed tired during the day
   - Never
   - A little of the time
   - Sometimes
   - Often
   - Very often

   □ 0 □ 1 □ 2 □ 3 □ 4

   4b. If your child experienced this, do you think it was related to PKU?
   - Yes
   - No
   - I don’t know

   □ 0 □ 1 □ 2
### YOUR CHILD’S HEALTH (continued)

#### 5a. In the past 7 days, I noticed that my child had trouble concentrating

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
<th>I don’t know, my child is too young</th>
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<tr>
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</table>

**5b. If your child experienced this, do you think it was related to PKU?**

- **Yes**
- **No**
- **I don’t know**

#### 6a. In the past 7 days, my child needed longer to think about things than other children their age

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
<th>I don’t know, my child is too young</th>
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</table>

**6b. If your child experienced this, do you think it was related to PKU?**

- **Yes**
- **No**
- **I don’t know**

#### 7a. In the past 7 days, my child was irritable or fussy

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<th></th>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
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**7b. If your child acted this way, do you think it was related to PKU?**

- **Yes**
- **No**
- **I don’t know**

#### 8a. In the past 7 days, my child became aggressive

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
<th>I don’t know, my child is too young</th>
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</tbody>
</table>

**8b. If your child acted this way, do you think it was related to PKU?**

- **Yes**
- **No**
- **I don’t know**

#### 9a. In the past 7 days, my child was moody

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
<th>I don’t know, my child is too young</th>
</tr>
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</tbody>
</table>

**9b. If your child acted this way, do you think it was related to PKU?**

- **Yes**
- **No**
- **I don’t know**
### 10a. In the past 7 days, my child seemed sad

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
<th>I don’t know, my child is too young</th>
</tr>
</thead>
<tbody>
<tr>
<td>□₀</td>
<td>□₁</td>
<td>□₂</td>
<td>□₃</td>
<td>□₄</td>
<td>□₅</td>
</tr>
</tbody>
</table>

**₁₀b. If your child seemed sad, do you think it was related to PKU?**

- Yes □₀
- No □₁
- I don’t know □₂

### 11a. In the past 7 days, my child seemed anxious

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Often</th>
<th>Very often</th>
<th>I don’t know, my child is too young</th>
</tr>
</thead>
<tbody>
<tr>
<td>□₀</td>
<td>□₁</td>
<td>□₂</td>
<td>□₃</td>
<td>□₄</td>
<td>□₅</td>
</tr>
</tbody>
</table>

**₁₁b. If your child seemed anxious, do you think it was related to PKU?**

- Yes □₀
- No □₁
- I don’t know □₂
YOUR CHILD’S PKU DIET AND SUPPLEMENTS

Following are some things that parents of children with PKU may think about the PKU diet and supplements (formula or medical food). For each sentence, please tick the box that best applied to you or your child.

By *supplement or amino acid mixture*, we mean the product or liquid (for example milk, powder) prescribed to your child by their doctor.

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. In the past 7 days, it was hard to get my child to take their supplements</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child doesn't take a supplement</td>
<td>○ 0</td>
<td>○ 1</td>
<td>○ 2</td>
<td>○ 3</td>
<td>○ 4</td>
</tr>
<tr>
<td>13. In the past 7 days, it was hard to make sure that my child followed their diet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child doesn't follow a PKU diet</td>
<td>○ 0</td>
<td>○ 1</td>
<td>○ 2</td>
<td>○ 3</td>
<td>○ 4</td>
</tr>
<tr>
<td>14. In the past 7 days, it was hard to make sure that my child got enough calories</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>My child doesn't follow a PKU diet</td>
<td>○ 0</td>
<td>○ 1</td>
<td>○ 2</td>
<td>○ 3</td>
<td>○ 4</td>
</tr>
<tr>
<td>15. In the past 7 days, I felt sad when I had to restrict my child's diet because of PKU</td>
<td></td>
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</tr>
<tr>
<td>My child doesn't follow a PKU diet</td>
<td>○ 0</td>
<td>○ 1</td>
<td>○ 2</td>
<td>○ 3</td>
<td>○ 4</td>
</tr>
<tr>
<td>16. In the past 7 days, I was worried that my child secretly ate food or drank things that they were not supposed to have</td>
<td>Never</td>
<td>A little of the time</td>
<td>Sometimes</td>
<td>Most of the time</td>
<td>Always</td>
</tr>
<tr>
<td>My child doesn't follow a PKU diet</td>
<td>○ 0</td>
<td>○ 1</td>
<td>○ 2</td>
<td>○ 3</td>
<td>○ 4</td>
</tr>
<tr>
<td>17. In the past 7 days, it was annoying to weigh or measure portions, or estimate protein (exchanges) in my child’s food</td>
<td>Never</td>
<td>A little of the time</td>
<td>Sometimes</td>
<td>Most of the time</td>
<td>Always</td>
</tr>
<tr>
<td>My child doesn't follow a PKU diet</td>
<td>○ 0</td>
<td>○ 1</td>
<td>○ 2</td>
<td>○ 3</td>
<td>○ 4</td>
</tr>
</tbody>
</table>
## YOUR CHILD’S PKU DIET AND SUPPLEMENTS (continued)

### 18. In the past 7 days, it was hard for me when my child had to follow the diet in front of others

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t follow a PKU diet</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
</tr>
</tbody>
</table>

### 19. In the past 7 days, I felt less spontaneous (less able to do something unplanned) because of my child’s PKU diet (for example eating out, visiting friends or family…)

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t follow a PKU diet</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
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</tbody>
</table>

### 20. In the past 7 days, it was hard for me to eat out because of my child’s PKU diet

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t follow a PKU diet</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
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</table>

### 21. In the past 7 days, my child followed their PKU diet

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t follow a PKU diet</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
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</tbody>
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### 22. In the past 7 days, my child and I argued because of the PKU diet

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<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t follow a PKU diet</th>
<th>Does not apply - my child is too young</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
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### 23. In the past 7 days, my child enjoyed eating even though they are following a PKU diet

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<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t follow a PKU diet</th>
<th>I don’t know, my child is too young</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
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<td>☐ 2</td>
<td>☐ 3</td>
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<td>☐ 5</td>
<td>☐ 6</td>
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### 24. In the past 7 days, I felt less spontaneous (less able to do something unplanned) because of my child’s supplements (for example eating out, visiting friends or family…)

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t take a supplement</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
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</tr>
</tbody>
</table>

### 25. In the past 7 days, it was hard for me to eat out because of my child’s supplements

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<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn’t take a supplement</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
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</tbody>
</table>
### YOUR CHILD’S PKU DIET AND SUPPLEMENTS (continued)

#### 26. In the past 7 days, my child and I argued because of their supplements

<table>
<thead>
<tr>
<th>Never</th>
<th>A little of the time</th>
<th>Sometimes</th>
<th>Most of the time</th>
<th>Always</th>
<th>My child doesn't take a supplement</th>
<th>Does not apply - my child is too young</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
<td>☐ 6</td>
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#### 27. In the past 7 days, my child missed taking some supplements

<table>
<thead>
<tr>
<th>Never</th>
<th>1 or 2 times</th>
<th>3 to 5 times</th>
<th>6 or 7 times</th>
<th>More than 7 times</th>
<th>My child doesn't take a supplement</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
</tr>
</tbody>
</table>
YOUR DAILY LIFE WITH YOUR CHILD’S PKU

Following are some things that parents of children with PKU may experience when living with PKU. For each sentence, please tick the box that best applied to you. If you did not do the activity, please tick the ‘Does not apply’ box.

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<tbody>
<tr>
<td>28. In the past 7 days, it was easy to plan my child's meals in advance</td>
<td>Not at all</td>
<td>A little</td>
<td>Somewhat</td>
<td>Very</td>
<td>Extremely</td>
<td>Does not apply</td>
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<td>0</td>
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<td>3</td>
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<td>5</td>
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| 29. In the past 7 days, it was time-consuming to prepare PKU meals (weighing, measuring, cooking) | Not at all | A little | Somewhat | Very | Extremely | Does not apply |
|   | 0 | 1 | 2 | 3 | 4 | 5 |

| 30. In the past 7 days, it was easy to cook special PKU low protein food | Not at all | A little | Somewhat | Very | Extremely | Does not apply |
|   | 0 | 1 | 2 | 3 | 4 | 5 |

| 31. In the past 7 days, it was time consuming to do PKU-related management tasks (filling in forms, making phone calls, reimbursements, etc) | Not at all | A little | Somewhat | Very | Extremely | Does not apply |
|   | 0 | 1 | 2 | 3 | 4 | 5 |

| 32. In the past 7 days, I missed work because of my child's PKU | Never | A few hours | 1 day | 2 to 3 days | 4 or more days | I don't work because of my child's PKU | I don't work |
|   | 0 | 1 | 2 | 3 | 4 | 5 | 6 |

| 33. In the past 7 days, my child's PKU impacted my work life (for example feeling distracted…) | Never | A little of the time | Sometimes | Most of the time | Always | I don't work because of my child's PKU | I don't work |
|   | 0 | 1 | 2 | 3 | 4 | 5 | 6 |

| 34. In the past 7 days, it was hard to do everything I needed to do for my child's PKU | Never | A little of the time | Sometimes | Most of the time | Always |
|   | 0 | 1 | 2 | 3 | 4 |

| 35. In the past 7 days, my child's PKU prevented me from doing things I needed to do | Never | A little of the time | Sometimes | Most of the time | Always |
|   | 0 | 1 | 2 | 3 | 4 |
36. It is inconvenient to carry my child’s supplements with me when we are going on holiday

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
<th>My child doesn't take a supplement</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

37. It is inconvenient to carry my child’s PKU food with me when we are going on holiday

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
<th>My child doesn't eat any special food</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
YOUR FEELINGS IN GENERAL ABOUT PKU

Following are some things that parents of children with PKU may feel. For each sentence, please tick the box that best applies to how you feel in general.

Generally:

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>38.</td>
<td>I am worried that my child's Phe levels are high</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>39.</td>
<td>PKU expenses (for prescription co-payments or special food) negatively impact my daily life</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>40.</td>
<td>Visiting my child's doctor/dietician for PKU bothers me</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>41.</td>
<td>PKU makes me angry</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>42.</td>
<td>It is hard having constantly to explain PKU to others</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>43.</td>
<td>PKU makes it hard for me to maintain friendships</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>44.</td>
<td>I am worried about how PKU might affect my child's future health</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>45.</td>
<td>Having a child with PKU influences or has influenced my decision to have other children</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
<tr>
<td>46.</td>
<td>It is easy for me to live with my child's PKU</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
</tr>
</tbody>
</table>
YOUR FEELINGS IN GENERAL ABOUT PKU (continued)

Generally:

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>47. I am confident that I have enough information about PKU and its treatment</td>
<td></td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>48. It is tiring to have to repeat explanations about PKU (diet, supplements, disease) to my child</td>
<td></td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>49. PKU negatively impacts my relationship with my partner</td>
<td></td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>50. I spend less time than I would like with my other child(ren)</td>
<td></td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>51. I feel guilty if my child eats something they are not supposed to</td>
<td></td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
<tr>
<td>52. I feel guilty if my child misses taking a supplement</td>
<td></td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
</tbody>
</table>
YOUR FEELINGS IN GENERAL ABOUT PKU (continued)

Generally:

| 53a. My child is afraid of having their blood taken from their arm |
|------------------|------------------|------------------|------------------|------------------|------------------|
| Not at all       | A little         | Somewhat         | Very             | Extremely        |
| □ 0              | □ 1              | □ 2              | □ 3              | □ 4              |

→ 53b. If your child is afraid, how bad does that make you feel? / how difficult is it for you?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
</tbody>
</table>

| 54a. My child is afraid of having their blood taken from their finger (finger prick) |
|------------------|------------------|------------------|------------------|------------------|
| Not at all       | A little         | Somewhat         | Very             | Extremely        |
| □ 0              | □ 1              | □ 2              | □ 3              | □ 4              |

→ 54b. If your child is afraid, how bad does that make you feel? / how difficult is it for you?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little</th>
<th>Somewhat</th>
<th>Very</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
</tr>
</tbody>
</table>

Please check that you have answered all the questions.

Thank you for taking the time to answer these questions.