PREPARATION FOR STUDY VISITS

How to prepare for the first (Baseline) and final (12 month) study visits

• The baseline and final study visits will include an overnight stay at Emory University’s Research Center. You will first come to the Emory Genetics Clinic on North Decatur Road before going to the Research Center.

• You do not have to be fasting when you arrive for the baseline and final study visits.

• Before arrival, you will complete a 3-day diet record. Record any nutrition supplements you take on your diet record!

• Bring with you:
  ➢ Any medications you are currently taking, and supplements you are currently taking
  ➢ Your medical food (formula) and your Kuvan™
  ➢ Any mixing ingredients for your medical food or Kuvan™!
  ➢ Movies to watch for the overnight visits
  ➢ Your insurance card
  ➢ Your log book for the final visit

• You will be asked to complete the medical update form IF there have been changes to at least one of the following:
  ➢ Your health care provider, your diet, your medicines, your exercise routine, your personal health

Special instructions for all other study visits

• You will need to be fasting (NPO) after midnight

• Before you arrive:
  ➢ Complete an overnight urine sample the night before the study visit
  ➢ Complete a 3-day diet record. Record any nutrition supplements you take on your diet record!

• Bring with you:
  ➢ Your log book
  ➢ Any new medications you are taking, and new supplements you are taking
  ➢ Your insurance card

• You will be asked to complete the medical update form IF there have been changes to at least one of the following:
  ➢ Your health care provider, your diet, your medicines, your exercise routine, your personal health

For Standard Care follow-up appointments at the Emory Genetics Clinic:

• You will need to be fasting (NPO) after midnight for your plasma amino acid test

• Before you arrive, complete a 3-day diet record. Record any nutrition supplements you take on your diet record!

• Bring with you any new medications you are taking, and new supplements you are taking

• Bring your insurance card with you to each visit
Schedule of study visits & standard care clinic visits

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<th>TYPE OF VISIT</th>
<th>WHEN</th>
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<td>Upon appointment</td>
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<td>Study Visit: Follow up</td>
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<td>Standard Care Visit (Responders only): Follow up</td>
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*Other standard care visits may be scheduled during this time by the dietitian or doctor so that your nutrition and health can be monitored properly.

- The BH4 & PKU study has 5 research visits total, but 7 anticipated visits for responders who will require standard care dietary adjustment. The Baseline (0 month) and End-of-study (12 month) visits will be the busiest and most time consuming. You will be asked to spend the night at the Emory Research Center for these two visits.

  **NOTE:** When you stay overnight at the Emory Research Center, you will have several options for dinner. We will contact you prior to the visit to ask which meal you would prefer.