

Collecting Blood at Home

How to take your blood Phe levels at home

A guide for people with PKU



An educational brochure brought to you by BioMarin Pharmaceutical Inc.

Taking Your Blood Phe Levels is Very Important

Your blood phe level tells you whether your PKU is under control. Keeping your blood Phe low and in control leads to a better life with lower risk of brain, mood or social problems.

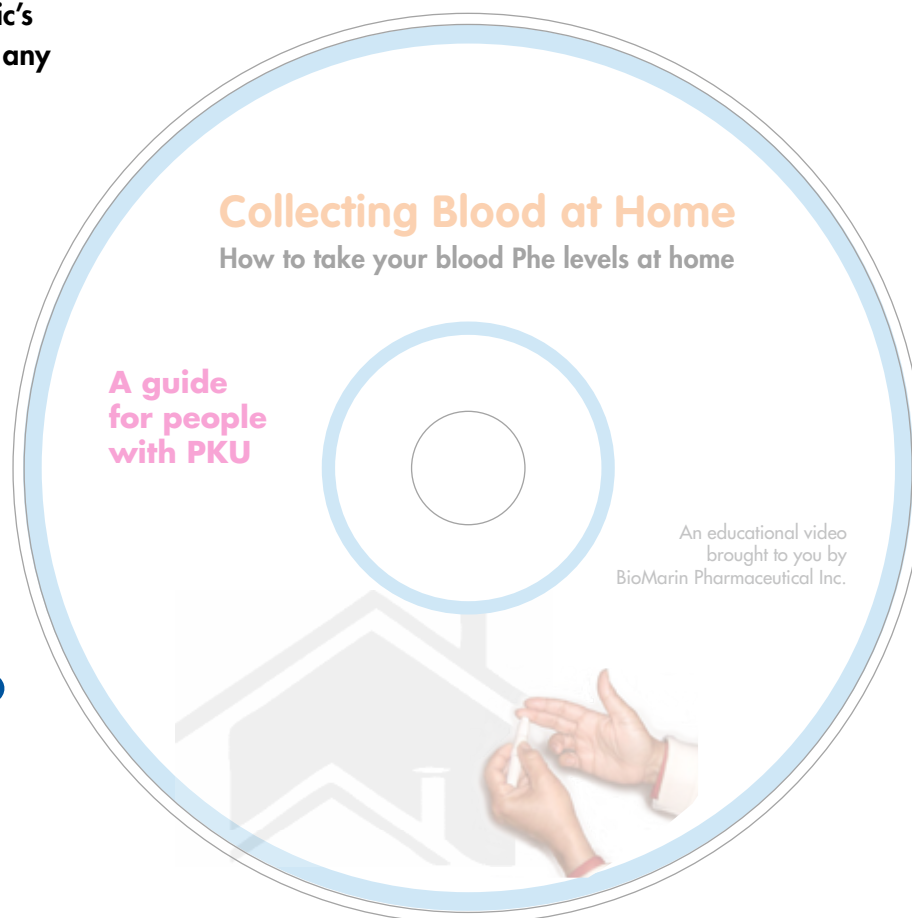
Many times your doctor or dietitian may take a blood Phe level during your clinic visit, but he or she may also ask you to take a blood Phe level at home in between visits or before starting a new treatment. Taking your blood Phe level at home is very important to ensure your treatment is on track.

In this booklet and video we provide you with clear instructions on how to take a blood Phe level at home. Please keep in mind that your clinic may have more specific instructions.

Always follow your clinic's instructions and discuss any questions with your clinician.

**Remember,
keep your
phe low and
in control**

Staying on top
of your blood
Phe levels
lets you be in
charge



Preparing for Your Blood Test

Before you Test > **Gather your supplies**



Spring-loaded Lancets

Available from your clinic by prescription or at your pharmacy

Note: Diabetic lancets will not work for a PKU test



Filter Paper Form

Available from your clinic



Regular & Moisture Resistant Envelopes

Available at office supply store

Optional Items



Biohazard Sharps Container

Available from your clinic by prescription or at your pharmacy



Alcohol Wipe



Band-Aids

Available at your local drug store



Heel or Hand Warmer

Taking Your Blood Phe Level at Home

The **STEPS** > A Quick Overview



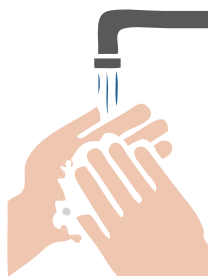
Don't forget, before you test:

- > Complete a diet record covering the 1-3 days before your blood test. Mail as instructed by your clinic.
- > Fill out the filter paper form with your personal information.

1. Wash hands thoroughly with soap and warm water and select the puncture site.
2. Position the lancet on the side of your finger. Press the lancet firmly on your skin at the puncture site. Turn the hand over and let a drop of blood form on your fingertip.
3. Fill filter paper circles with blood.
4. Let filter paper specimen dry completely (2-3 hours).
5. Discard waste following local regulations.
6. Mail completed form to the testing laboratory within 24 hours of collection.

Taking Your Blood Phe Level at Home

The STEPS > Details



1. Wash Your Hands

Wash your hands thoroughly with soap and warm water. Dry with a clean towel. *Note: You may use an alcohol wipe to clean the puncture site, but if you do, you will need to discard the first drop of blood before applying to filter paper.*

2. Use Lancet to Prick Finger

Select a puncture site. Try to use the sides of the fingertips as the tops are very sensitive. Choose a different puncture site each time you test. Repeated punctures in the same spot may cause soreness and calluses. Then, press the opening of the lancet firmly against the puncture site and push down on the trigger. Carefully lift the lancet away from skin without smearing the blood sample. Turn the hand over and let a drop of blood form on your fingertip.



Diabetic lancets will not work for a PKU test.



Generally, babies are tested on the heel. Confirm with your clinic on the testing site for your child.

Taking Your Blood Phe Level at Home

The STEPS > Details



3. Fill the Filter Paper

Fill filter paper circles completely with blood by applying gentle pressure to the puncture site so that the blood drops onto the filter paper. Do not actually touch the finger to the paper. In fact, the finger and the paper should not touch anything at all to avoid contamination of the sample.

Do not squeeze the finger too hard as this can dilute the blood. The drop should become so large that it falls freely from the finger and should nearly fill the circle on the sample paper.

Fill from one side only, but make sure that there is enough blood to soak through to the other side. Blood should be visible from both sides of all the circles. To stop bleeding press finger with a clean paper towel or gauze; use a Band-Aid if necessary.

Blood Spot Check



Incorrect



Incorrect



Correct!

Taking Your Blood Phe Level at Home

The STEPS > Details

4. Let Filter Paper Dry

Let filter paper specimen air dry completely (2-3 hours). Choose a safe place where the filter paper will not be contaminated. Be careful that the paper is not placed on a surface where the blood will soak through. It is best to pin up the filter paper on a bulletin board or put it somewhere out of reach.



5. Discard Materials

Place the used lancet in a container for sharp objects. It is important to discard the used lancet carefully after each use to avoid unintended lancet stick injuries. Local regulations vary on how to dispose of this type of waste. Please ask your clinic or pharmacist for guidance on how best to take care of disposal. Used filter paper and lancets may be considered biohazardous waste in your area.

6. Mail Filter Paper to the Lab

Mail the completed form to the testing laboratory **within 24 hours** of collection. Either mail the sample to the laboratory address provided by your clinic or hand-deliver it to the laboratory. If you forget to mail the filter paper form, check with your clinic to find out if the specimen is still okay to be analyzed. Sometimes the lab can still analyze a sample up to a week after being collected. But remember to send it in within a day of collection for the next test.

Taking Your Blood Phe Level at Home

The STEPS > Details

Always follow your clinic's instructions for mailing the filter paper to the lab.



Moisture resistant envelopes are waterproof and will protect the sample from damage. They can be purchased at most stationary stores.

Mailing Instructions:

1. Put the filter paper into a moisture resistant envelope.
2. Mark the envelope with the clinical laboratory address
3. Mark on the envelope the following:

**ATTENTION: SPECIMEN PROCESSING
CLINICAL SPECIMEN ENCLOSED**

Problem Solving Tips

If you have difficulty getting enough blood to fill the minimum of 2 circles:

1. It is easier to get blood from warm hands. Try **rinsing your hands under warm water** or holding a warm object (e.g., mug of tea, heating pad, towel, etc.). Warmth encourages blood to flow more freely.
2. **Use gravity.** Shake your hands downward or simply hold them below waist level until you can feel the blood flowing into the fingertips.
3. **Massage your fingers** to get the blood flowing to the tips.
4. **Use your power of concentration.** Imagine the blood flowing into your fingertips. This really works!
5. **Try different puncture sites.** Some people like to use the sides of the tip of the finger because there are less nerve endings there. Others like to use the tips of the fingers because, even though it may hurt more, they get all the blood they need from only one poke.
6. You may have to **adjust the lancet** to a deeper setting to get a large enough drop of blood.

Problem Solving Tips

Sometimes filter paper specimens are rejected. Here are some ways to avoid invalid samples:

1. **Allow the filter paper to dry completely** before mailing.
2. **Fill circles completely**, so that the blood is visible from both sides of the paper.
3. **Do not over-saturate the circles.** This can happen when drops of blood are layered one on top of the other.
4. **Clean skin thoroughly** before testing.
5. **Mail the specimen as soon as it has dried.** Specimens must be received within 2 weeks after the day of collection.



And remember:

Always follow your clinic's instructions. This booklet is designed to be a basic guide. If you have any questions, talk to your doctor or dietitian.

**BioMarin is here to help you manage your PKU.
Check out this great resource for people just like you:**

PKU.com

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