

# **SO YOU HAVE DECIDED TO DONATE YOUR CHILD'S BLOOD TO THE NIGMS REPOSITORY AT CORIELL**

**You've been given one of our shipping kits. Now what?**

You need to schedule an appointment with your child's physician for the blood draw. If you already have a procedure and/or appointment scheduled, bring the kit with you when you go. It might be a good idea to let the office know ahead of time that you want to do this. Doctors always appreciate the heads up.

## **The shipping kit contains the following things:**

1. For the specimens themselves we've included **two small pediatric tubes** (also known as vacutainers) for your child and **four large tubes** (two for Mom and two for Dad) in case you would like to contribute your blood along with your child's. The parental blood is not necessary, but if you would like to donate it, it will certainly enhance the value of this collection. The empty tubes are in **bubble wrap sleeves** for their protection. We ask that the filled tubes get packed back into those sleeves. You should label your child's tubes with his or her PA# from the questionnaire and any parental tubes with the words Mom and/or Dad. Also put the draw date on the tubes. We've included a roll of tape to wrap around the tube at the top to keep the rubber stoppers in place. Just go around the tube top once. Don't over do it. Place the tubes in the bubble wrap sleeves, place the bubble wrap in the clear plastic biologicals bag and put that bag inside the white Tyvek bag. I know that seems like a lot of cushioning, but these tubes are valuable and we don't want them broken.
2. Now for the seemingly endless amount of **paperwork**.

First and most important is our **Coriell Model Consent Form**. You need to sign this before the blood sample is drawn, thus you are giving consent for your child to be bled. You do not need to send us a blank copy also. That is a direction for researchers sending us specimens, not parents like yourself.

Second in importance is the **Propionic Acidemia Questionnaire**. Your child has been assigned a PA number by Jill Franks (subject identifier). It should already be on the questionnaire. When the blood reaches Coriell, it will be assigned a Repository reference number by our staff. These two numbers will be linked in our database, but there will be no use of your name. Please try to fill in the questionnaire with the information you know and have your physician help fill in the rest. A complete history on your child is very valuable to the researchers who will be using these specimens.

Third is the **NIGMS Submission Form**. We do not need one filled in for your child. These are to be used only if you decide to send us parental blood as well as your child's. We need one of these Submission Forms for each parent filled in with just the basic data on the first page (age, gender, and ethnic origin). You do not need to worry about the other pages.

3. A **cardboard box within which is a styrofoam box (liner)**. The styrofoam insulates the blood specimens from both heat and cold. Blood tubes should be kept at room temperature after the samples have been drawn. Even health care professionals think they should go in the refrigerator. Not true! You wouldn't want to be refrigerated....your blood doesn't either. Please remove the "empty container" labels from the outer box. We've included **bright stickers** for you to put on the outside cardboard box when you ship it back to us that say "no heat or cold" and "do not delay biologicals". Please use all of them.
4. A **Federal Express shipping slip** has been filled out for you to use to ship the box back to Coriell. We are picking up the charge, so don't worry about the cost. Please write in your name and address in the "sender" section. There is a **clear plastic sleeve** with an adhesive strip on the back. Peel and stick the sleeve onto the sealed box (any heavy tape, even duct tape, will do to seal the box) and put the Fed Ex slip into the sleeve. Fed Ex will pick up the package, if you give them a call. You may also drop the package off at one of their local offices.
5. We have included a **shipping instructions/notification sheet**. Most of these instructions have been mentioned above. The enclosed instruction sheet is a bit more technical in nature. Read it, if you must. On the back of the shipping instructions sheet is a place to put the Fed Ex tracking number (a 12 digit number to be found at the top of the Fed Ex slip we included in the kit. Feel free to track your package's progress using this number at the Fed Ex online site, but Coriell needs to be either faxed this notification sheet or you need to email us to let us know when the box got shipped and what the tracking number is. Both the Fax number and the Project Manager's email address are included on the sheet. Please do one or the other. We really do need to know when the shipment is on the way.

**That's all there is to it. Thank you for going to all this trouble just to help us out.**