

## Visit 6: Taking Charge of Your Medical Care-What's Left to Learn?

**Objective:** At this visit you will have the opportunity to review a summary of your neuropsychological testing results. We will revisit your transition questionnaire, to help you and your family identify what steps are left in the transition process and develop a plan. You will also have the opportunity to discuss how your health care will change.

In this section:

- Transition Questions
- Bright Futures: Late Adolescence Visits
- Frequently Asked Questions About Health Care Transition
- MEDLINEplus Guide to Healthy Web Surfing:  
[www.nlm.nih.gov/medlineplus/healthywebsurfing.htm](http://www.nlm.nih.gov/medlineplus/healthywebsurfing.htm)
- 10 Things to Know About Evaluating Medical Resources on the Web:  
[nccam.nih.gov/health/webresources](http://nccam.nih.gov/health/webresources)

At this visit:

- Nutrition assessment- bring your 3 day food record to clinic
- Physical assessment-a brief visit with PKU doctor
- Future plans (e.g., college, vocation training, living arrangements, financial arrangements) discussed
- Neuropsychological assessment feedback
- Confirm next visit

Who is involved:

- **You**
- Your support team
  - Your parents
  - PKU clinic physician
  - PKU clinic psychologist
  - PKU clinic nutritionist



Cristine M. Trahms Program for Phenylketonuria  
University of Washington - CHDD - Box 357920, Seattle, WA 98195

(206) 598-1800, Toll Free in Washington State 877-685-3015  
<http://depts.washington.edu/pku>

## Transition Questions

Over the last year and a half, you have considered many of the aspects of living independently, including health care and PKU management. Congratulations!

Now, it is time to look again at your plans. Take pride in the plans that you have already made. Consider what is left to decide.

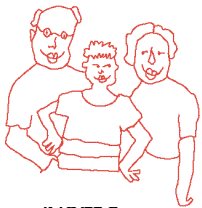
Take some time to consider these questions:

- What are your plans after high school? Work? Training? College? Will PKU affect these plans?
- Where will you live? How will PKU affect this?
  - Will you need to be near a large medical center to receive specialty health care?
  - Where is the doctor in the community where you will live? What about transportation?
  - Where will your formula come from?
- What will you eat?
  - How will you prepare your formula and food?
  - Where will you get your formula? Where will you get low protein food?
  - How will you handle social situations?
- What about money?
  - How will you pay for where you live? For what you eat?
  - How will you pay for medical care and prescriptions?
- What else do you need to consider?



Cristine M. Trahms Program for Phenylketonuria  
University of Washington - CHDD - Box 357920, Seattle, WA 98195

(206) 598-1800, Toll Free in Washington State 877-685-3015  
<http://depts.washington.edu/pku>



## LATE ADOLESCENCE VISITS (18, 19, 20, and 21 Years)

Name \_\_\_\_\_

Age \_\_\_\_\_ Weight \_\_\_\_\_ Height \_\_\_\_\_

**Bright Futures**



### At Today's Visit

- ★ Your health professional will ask for an update on your health.
- ★ You will have a physical examination and may be asked to give a urine sample.
- ★ You will be asked about your family's history of heart disease, and your blood pressure will be checked.
- ★ You will be given instruction on how to perform a breast self-exam or testicular self-exam.
- ★ Your vision and hearing may be checked.
- ★ You may be checked for anemia (iron-poor blood).
- ★ You may have a blood test and/or a test for tuberculosis.
- ★ You may receive one or more immunizations. Ask your health professional about them.
- ★ If you are sexually active, you will be checked for sexually transmitted diseases (STDs).  
If female, you may have a pelvic exam.
- ★ You will have an opportunity to ask questions.

### Things You May Want to Discuss During This Visit

- ★ Changes in your family or living situation since your last visit.
- ★ Issues about your size, shape, and weight.
- ★ How physically active you are.
- ★ Your plans for the future: school, college, work.
- ★ Living on your own, being more independent.
- ★ Issues about violence, guns, drugs, and alcohol.
- ★ Relationships, sex, and contraception.
- ★ Any other topics you may want to discuss.

---

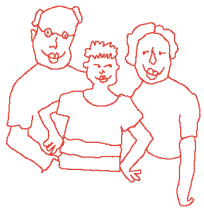
---

---

---

**Notes:**





## LATE ADOLESCENCE VISITS (18, 19, 20, and 21 Years)

Name \_\_\_\_\_

**Bright Futures**



### Things to Keep in Mind Between Now and the Next Visit

- ★ Do some kind of physical activity for 30 to 60 minutes at least three times a week.
- ★ Always wear a safety belt, follow speed limits, concentrate, and avoid distractions when driving. Do not drink and drive.
- ★ Recognize when you are feeling stressed, angry, or sad, and seek help.
- ★ Eat three nutritious meals a day. Choose healthy snacks and limit sugar and high-fat foods.
- ★ Visit your dentist regularly and learn what to do in a dental emergency.
- ★ Talk with your health professional and educate yourself about sexuality (including sexual orientation), contraception, abstinence, safer sex, and STDs.
- ★ Avoid smoking, chewing tobacco, alcohol, drugs, diet pills, and steroids.
- ★ Do not carry or use a weapon of any kind.
- ★ Maintain good relationships with your family, peers, and siblings, and develop other social support systems.
- ★ Review job safety rules and follow safety procedures.
- ★ Learn how to be an informed health care consumer and use the health care system.
- ★ Identify your talents, skills, and interests, and make plans for a career or education.



### How to Prepare for the Next Visit

- ★ Keep track of illnesses and injuries, including visits to other health facilities and the emergency room.
- ★ Update your health and immunization records.
- ★ Be prepared to discuss any changes in your family, home, or living situation.
- ★ Prepare and bring in questions about substance abuse, sexuality, and mental and physical health.
- ★ Keep a list of topics you would like to discuss at your next visit.
- ★ Share ideas with the health professional about community resources that you have found useful.

### What to Expect at the Next Visit

- ★ You will have a physical examination and may be asked to give a urine sample.
- ★ You will be asked about your family's history of heart disease, and your blood pressure will be checked.
- ★ You will be given instruction on how to perform a breast self-exam or testicular self-exam.
- ★ Your vision and hearing may be checked.
- ★ You may be checked for anemia (iron-poor blood).
- ★ You may have a blood test and/or test for tuberculosis.
- ★ You may receive one or more immunizations.
- ★ If you are sexually active, you will be checked for STDs. If female, you may have a pelvic exam.

## Frequently Asked Questions About Health Care Transition

Adapted from: Pearson T. Getting the most from health-care visits. Diabetes Self-Management, 2001.

### How will my health-care change as I transition from pediatric to adult health care?

As a child, most of your health care was provided by a **pediatrician**. For adults, most health care is provided by a **primary care physician (PCP)**. A PCP is a usually doctor and is usually a **family practice doctor**, an **internal medicine doctor** (or an internist), or a **generalist**. A PCP might also be a **nurse practitioner (ARNP)** or a **physician's assistant (PA)**.

As a child, PKU was managed by your PKU Clinic. This is an example of a **specialty clinic**. Your parents probably needed to get a referral from your pediatrician to make sure that your visits to the PKU Clinic and formula/medical food were covered by insurance. As an adult, your PKU will also be managed by a specialty clinic, the Adult PKU Clinic. You will be responsible for getting a referral from your PCP.

### What does a Primary Care Provider (PCP) do?

Your primary care provider (PCP) will do many of the same things that your pediatrician does, for example, taking care of you when you are sick or injured and making referrals when you need specialty care. He or she is the coordinator for your medical care. Your PCP has probably never worked with an adult with PKU. Therefore, you will need to educate him or her about PKU. (When you were an infant, your parents educated your pediatrician about PKU; now it's your turn.)

### What will happen at an appointment with my Primary Care Provider (PCP)?

When you meet with a primary care (probably a medical doctor, but possibly a nurse practitioner) for the first time, you will most likely be asked many questions about your health and be given a complete physical exam. You may also be asked to fill out a **written health questionnaire**. Be prepared to talk about (or write down information about) your **personal and family health history**, and any **recent illnesses**. You should also be prepared to talk about PKU and PKU management. **You may want to contact your PKU Clinic ahead of time, and take some written information for your PCP.**

Your primary care provider will want to know what drugs and supplements, if any, you currently take, so bring a list of the names and doses of all the prescription medicines, over-the-counter products, vitamins and minerals, and other dietary supplements you take. You should also take information about your formula/medical food prescription. You can also just put all your pill bottles in a bag and bring it with you. Your provider may also ask about your level of physical activity and your diet.



Cristine M. Trahms Program for Phenylketonuria  
University of Washington - CHDD - Box 357920, Seattle, WA 98195

(206) 598-1800, Toll Free in Washington State 877-685-3015  
<http://depts.washington.edu/pku>

## **How do I prepare for an appointment with my Primary Care Provider (PCP)?**

To make sure you get the most out of your visit with your primary care provider, do some work ahead of time:

- Know what you want to get from the appointment when you walk through the office door. Spend time thinking about what you would like to ask or tell your health-care provider; write these thoughts down (and take your list to the appointment). Try to prioritize your questions so that you ask the most pressing first.
  - What are your goals?
  - What concerns do you have about your health?
  - What would you like to know about your doctor?
- Anticipate what information your provider is likely to want from you. Gather information you may need to bring with you, for example:
  - The names of your prescription medication (or take the pill bottles)
  - The names of any supplements or over-the-counter medications that you take
  - Your formula/medical food prescription and a description of your food pattern
  - A summary of your previous blood phe levels.
  - Contact information for the PKU Clinic and any other specialists you are seeing

## **What does my PKU Clinic do?**

Your PKU Clinic helps you with managing PKU. The Adult PKU Clinic is made up of a doctor, nutritionist, and social worker who all have training in PKU and other metabolic disorders. The clinic staff can help you to interpret your blood phe levels and adjust your food and formula pattern, if necessary. The staff at your PKU Clinic may also be able to help you find resources about PKU and/or resources to help you with management. The PKU Clinic can also help you to answer questions about PKU that your primary care provider may have.

## **What will happen at an appointment with my Specialty Clinic (PKU Clinic)?**

Appointments with the Adult PKU Clinic are different than with the pediatric clinic. You will meet individually with a doctor, nutritionist, and social worker. The PKU team will ask about management since your last visit, and will be able to answer questions that you may have. You will have a brief neurologic exam, similar to the exam at the pediatric clinic. The PKU Team will also help you with management issues, if necessary. You will probably have a blood draw at the lab, and the social worker or nutritionist will follow-up with you when the blood phe level is available.



Cristine M. Trahms Program for Phenylketonuria  
University of Washington - CHDD - Box 357920, Seattle, WA 98195

(206) 598-1800, Toll Free in Washington State 877-685-3015  
<http://depts.washington.edu/pku>

## **How do I prepare for an appointment with my Specialty Clinic (PKU Clinic)?**

To prepare for the visit, keep a food diary where you write down everything you eat, including portion sizes for several days. Also be prepared to describe how you prepare your formula/medical food and what your allowed phe is per day.

Bring a written copy of your food record with you to the appointment, along with any notes you've made about difficulties sticking with your prescribed food pattern. If you have specific questions about PKU, write them down ahead of time, and bring them to your appointment.

## **What do I do if I get sick?**

If you get sick, call your primary care provider, not the PKU clinic. It is helpful to have complete information available in order to help the person know how to better help you. Be prepared to describe the problem, when it began, and your symptoms.

It is helpful to talk to your primary care provider before you get sick about developing a plan for what to do when you are sick. (You may also want to talk to your PKU provider about your plan.)

Your plan for illness might include:

- Making sure you get enough fluid
- Making sure you continue to drink your formula
- Instructions for taking your temperature
- A list of over-the-counter drugs you can take for specific symptoms
- Instructions on when to call your doctor's office.
- Phone numbers for your doctor and friends you can call on for help

## **Staying Healthy**

The best way to manage your PKU and avoid problems is to stay healthy. Take good care of your body by avoiding health risks such as smoking and drinking. Promote a healthy body by exercising regularly, keeping blood phe levels low and getting enough sleep. Get help developing a meal pattern for formula/medical food and food. Check your blood phe level monthly. Educate yourself – it will help you ask better questions and make better decisions about your self care.



Cristine M. Trahms Program for Phenylketonuria  
University of Washington - CHDD - Box 357920, Seattle, WA 98195

(206) 598-1800, Toll Free in Washington State 877-685-3015  
<http://depts.washington.edu/pku>

## Assessment of the PKU Adolescent Transition Curriculum

### Session 6.

Objective: At this visit you will have the opportunity to review a summary of your neuropsychological testing results. You will have an opportunity to take another look at your transition questionnaire and discuss what steps you have left in the transition process.

I. Please tell us three things that you have learned during this visit

1)

---

2)

---

3)

---

II. What is your primary goal for future education or employment?

---

III. Which tasks of independence have you 'taken on' for yourself since the first transition visit?

---



Cristine M. Trahms Program for Phenylketonuria  
University of Washington - CHDD - Box 357920, Seattle, WA 98195

(206) 598-1800, Toll Free in Washington State 877-685-3015  
<http://depts.washington.edu/pku>