Dear Young Adult,

Congratulations on beginning the transition from the Pediatric (child) to the Adult PKU Clinic. Your first transition visit is scheduled for _________. We look forward to having you begin the process with the support of your parents.

The goal of this transition is for you to develop a personal plan for becoming responsible for your health care and PKU management. To accomplish this we have identified eight visits. Each visit focuses on a specific skill needed for independent PKU management. In addition, every visit will include a nutrition assessment. When the process is finished, you will have a complete reference notebook to help you manage PKU as an adult. The material for each visit builds on previous sections.

- During the first visit we will talk about the process of transition. In order to know what independence transition skills you already possess, you will complete an independence capability form.

- The second visit will focus on food. You will review keeping an accurate food record and calculating your phenylalanine intake. You will also complete an activity that will reinforce these skills.

- The third visit will be a continuation of the second, in which you explore recipe modification and eating out with PKU. The goal is to learn how to modify recipes and menu options to make it appropriate for a low phe food pattern.

- At the fourth visit you will learn about making decisions and solving problems. After learning about the steps involved in problem solving, you will complete two problem-solving activities and take more home for practice.

- High-risk behaviors and how they relate to PKU will be addressed during the fifth visit. You will also have an opportunity to consider how PKU affects your decisions about reproduction.

- During visit six you will complete a neuropsychological assessment and review PKU and adult cognitive function.

- During the seventh visit you will have the opportunity to explore the skills needed to manage your health insurance. You will also learn how to obtain reliable health information from the internet.

- At the last visit you will have the opportunity to complete your transition questionnaire, finalize a plan for independent living, complete your clinical treatment summary and sign your Adult PKU contract.

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

This packet is introductory material. *Please bring this material to your first visit*.

The first page compares and contrasts pediatric health care and adult health care: basically where you are now and where you are headed. Noting the differences will help you identify the skills that will be necessary in order to transition to the adult health care setting. Review this list and mark any areas in which you have questions.

The next page is a group of questions aimed to have you think about your personal transition process. The transition process will be different for each person. By thinking about the questions listed, you will have a better idea of what this process will look like for you. A page of suggestions for transition to adult health care follows these questions.

Also included in this packet is a group of pages taken from the Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents. The first in the group is a diagram outlining the expected health supervision outcomes over time. Social, developmental, and health outcomes are summarized along a continuum ending with the independence of the patient. The remaining pages give guidance to both you the adolescent and your parent as you enter the transition process. This information is intended for 15-17 year olds. These transition guidelines are all encompassing.

Finally, an annual patient agreement is included in order to allow you and your parents time to read it before the first visit. After answering any questions you might have, we will collect the signed agreement at the first visit.

The information in this guide is aimed primarily at you—because you will be responsible for your health and for managing PKU. Some information is intended for your parents—they've helped manage your PKU for many years and can help as you make this transition. It is important to go over all of the information with your family and to make decisions together.

We look forward to working with you on this exciting milestone.

The PKU Clinic Team:

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PKU
Seattle
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# PKU Transition Curriculum
## Table of Contents

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## Visit 5: Genetics and Reproduction

- High Risk Behaviors
- PKU and Adult Cognitive Function
- Phenylketonuria and Pregnancy

## Visit 6: Neuropsychological Assessment

- Neuropsychological Testing at the PKU Clinic: Frequently Asked Questions

## Visit 7: Taking Charge of Your Medical Care-What’s Left to Learn?

- Transition Questions
- Bright Futures: Late Adolescence Visits
- Frequently Asked Questions About Health Care Transition
- MEDLINEplus Guide to Healthy Web Surfing
- Insurance Primer
- Health Insurance Terms
- Rate Your Independence Capability
- Resources: www.kaisernetwork.org, www.kff.org/consumerguide

## Visit 8: Finalizing Transition

- Summary of Treatment for Phenylketonuria
- Effective Problem Solving: Formula Payment
- The Adult PKU Clinic
- Clinic visits and blood phe levels
- Health care provider information
- Appointment log
- Insurance information
- Medical expenses
- Immunization record
- Bright Futures: Anticipatory guidance for the adolescent
- Bright Futures: Anticipatory guidance for the parent(s)
- Resources
- Adult PKU contract

# Pediatric vs. Adult care: How do they differ?

Health care for children is different than health care for adults. So, it makes sense that PKU clinic for children is different than PKU clinic for adults. This table describes some of the differences. Mark the items in the adult care column that you have questions about.

| **Pediatric Care – Where you are now** | **Adult Care – Where you will be** |
|---|---|
| Pediatric PKU clinic | ☐ Adult PKU clinic |
| Parents are in charge | ☐ Care is self-directed |
| Care is monitored by parents and health care providers | ☐ Care is self-monitored and supported by health care providers |
| Appointments are scheduled | ☐ Adult must schedule own appointment |
| Support services are offered for financial and emotional issues | ☐ Adult must seek support services for financial and emotional issues |
| Parents are responsible for finances and payment | ☐ Adult is responsible for own finances and payment |
| Parents have insurance | ☐ Adult must have own insurance |
| Transportation provided by parents | ☐ Adult must provide own transportation |
| Parents request information about treatment | ☐ Must request own treatment information |
| Parents request information about outcome | ☐ Must request own information about outcome |
| Public health nurse services are available to help with day-to-day management | ☐ No public health nurse services are available |
| Pediatric specialty | ☐ Medicine Clinic |
| Education about reproduction concerns offered | ☐ Adult should make informed reproductive/contraceptive decisions |

We don't expect you to have mastered all of these skills…yet.

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## Transition Questions

Transition means change. Transition from youth to adulthood involves many factors: education, employment, finances, home living, community living, recreation and leisure, post-secondary education, and personal responsibility. Often, health is not considered as an important part of transition planning…even though health influences all areas of life. Part of the transition from youth to adulthood includes preparing for a change in health care.

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?

These issues may seem overwhelming. The transition process is designed to help you find the answers to these (and other) questions about health care and PKU management.

## Suggestions for parents as they help young adults plan for transition in health care:

1. Talk with your son or daughter about health care. Learn what he or she thinks about managing his or her own care.
2. Identify the health care skills that your son or daughter can perform, the skills he or she needs to learn, and the skills that require assistance. Develop a plan to help your child learn the necessary skills.
3. Identify people who can address health issues in planning transition for your son or daughter. These may be physicians, nurses, nutritionists, teachers, or family members.
4. Consider naming a physician who can take over the health care of your son or daughter, once he or she is an adult. Meet with the doctor, so he or she is familiar with your young adult's needs.
5. Identify a health advocate, if needed. It can be a family member or a friend who will interact with health care providers on behalf of the person who may need assistance.

## PKU Program
## University of Washington, Box 357920
## Seattle, WA 98195
## Transition Patient Agreement for Adolescent with PKU

Please read the following information carefully. If you have any questions regarding the program or its services, please contact the PKU Clinic at 206-685-3015 or toll-free at 1-877-685-3015.

Phenylketonuria [PKU] is a metabolic disorder that can cause intellectual disability if not consistently treated with specific dietary therapy. The best possible outcome for a child with PKU is normal physical and intellectual development. This outcome is achieved if blood phenylalanine levels are consistently maintained between 1-6 mg/dl on a long-term basis. Children and families who participate in clinic activities and children who learn to effectively manage their own diet are more likely to maintain acceptable blood levels and have more successful outcomes.

PKU Program benefits are available to all children with phenylketonuria [PKU] in the State of Washington. The PKU Program's recommended treatment and monitoring includes:
1. **Nutrition:** quarterly nutrition assessments, nutrition counseling, dietary guidance, and nutrition self-management skills curriculum
2. **Medical:** quarterly neurological exam, annual prescription for formula, and coordination of general health care with primary care physician regarding PKU management
3. **Social work:** quarterly parent discussion group, help with coordinating financial support for formula and clinic visits, coordinating clinic appointments, and interfacing with appropriate community agencies
4. **Psychometric testing:** developmental guidance and evaluation of cognitive functioning as described by the treatment protocol
5. **Blood phenylalanine reporting:** Regular reporting of levels to you and your child

I, _______________________request services for my child _________________ from the PKU Program at the University of Washington. I understand that if any of the following occur, my child will lose eligibility for services through the University of Washington PKU Program including some benefits funded by the State of Washington.

1. If I and my child move away from the State of Washington
2. If I fail to make clinic visits or follow-up appointments for my child as necessary for effective management of my child's PKU.
3. If I fail to supply enough blood phenylalanine levels to effectively manage my child's PKU. *

*Typically blood samples are requested monthly for children 6 months through adulthood.

4. If I fail to take personal responsibility for the cost of the PKU formula for my child by failing to secure insurance coverage for formula and clinic visits through my work; or if I fail to apply for medical coupons, to the Washington Basic Health Plan, or complete a CSHCN application.

We ask that you notify the PKU Program when you change addresses and/or telephone numbers. For billing purposes, we must know about changes in insurance coverage. We request that you provide appropriate referrals and authorizations from your child's primary care provider.

I recognize that participation in the PKU Program is voluntary and I can seek care for my child from other medical sources in Washington. I recognize that the PKU Program works in cooperation with the Washington State Department of Health in obtaining formula for my child. If I voluntarily elect to or fail to participate in the PKU Program, formula is available from other health care providers on a prescription basis.

My child and I will attend the PKU Transition Clinic quarterly [four times/year]. We will telephone to reschedule if we are unable to make one of our predetermined clinic appointments as scheduled below.

I will work with my child to provide monthly blood phe levels.

By signing I agree to comply with the conditions of the Patient Agreement.

Signature of Parent Date

Signature of Child Date

Signature of Health Care Provider Date

Original to medical record
Copy to client
Rev 12/02