

Visit 8: Finalizing Transition

Objective: At this visit you will have the opportunity to finalize a plan for independent living, complete the formula payment problems solving activity, visit the adult clinic facilities, and meet the Adult PKU clinic team.

In this section:

- Clinical Treatment Summary
- Formula Problem Solving
- 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)
- Adult PKU contract

At this visit:

- Nutrition assessment- bring 3 day food record to clinic
- Physical assessment- a brief visit with PKU doctor
- Discussion/role playing for ordering formula
- Provide documentation for post-high school plan *
- Meeting with Adult PKU Clinic Team and Adult Clinic Facilities
- Schedule visit with Adult PKU Clinic
- Medical Record Summary

Who is involved:

- **You**
- Your support team:
 - Your parents
 - PKU clinic physician
 - PKU clinic social worker
 - PKU clinic nutritionist

Summary of treatment for Phenylketonuria

Date of summary:

Name :

Birthdate:

Age:

Address:

Telephone:

I. Health status:

General health

Specific concerns

II. PKU Treatment History

Age at Dx:

Blood phe levels:

Mean blood phe level for last two years:

Range:

III. Current Treatment for PKU

Phenylalanine prescription:

Medical food prescription:

Medications:

Comments:

Example of Effective Problem Solving

PROBLEM:
Formula payment

What's the concern? What do I want?

I recently received a bill for my formula. I don't have the money to pay it but I still need my formula for next month. What should I do?

What could I do?

- a. Ignore the bill
- b. Call them and tell them I already paid it
- c. Borrow money to pay the bill
- d. Call my insurance company
- e. Stop taking my formula

Think it over

- a. I may not be able to get formula for next month
- b. I would feel guilty for lying
- c. I could do this, but I don't know whom I would borrow money from.
- d. I will need to know my insurance coverage and spend time finding out about available resources
- e. Too dangerous – my health would suffer

Make a decision

The best thing for me to do is to call my insurance company and find out what is available for assistance.

Do it!

How did it work?

The Adult PKU Clinic

The Adult PKU Clinic is a bit different than the Pediatric PKU Clinic that you and your family are used to. The main differences are 1) where clinic is held, 2) the PKU team you will work with, and 3) the format of the clinic.

Where is the Adult PKU Clinic?

The Adult PKU Clinic is held at the University of Washington Medical Center in the Lipid and Nutrition Clinic within the Medical Specialties Clinic. Basically, that means the clinic is across the street from the CHDD. The Medical Specialties Clinic is located on the third floor of the hospital and at the top of the outside set of stairs across from the CHDD.

Who are the people on the Adult PKU Clinic team?

- **Janet Garretson, MSW** is the person who has a role on both the Pediatric PKU Team and the Adult PKU Team. She will introduce you and your parents to the Adult PKU Team members. She will also be present at each of your clinic visits and help you with problem solving around insurance and formula.
- **Judy Brown, MS, RD** is the Adult PKU Clinic nutritionist. She will see you at each clinic visit and work with you to be sure that you are well nourished and have good blood levels.
- _____, **MD**. This will be a big change for you. At each clinic visit you may see a different doctor because the doctors rotate through the clinic. This means that you will need to think about what information you need from a doctor at your visit and prepare your questions.

How do I make an appointment in the Adult PKU Clinic?

Initially Janet Garretson, MSW will make the appointments for you. These appointments will be between 9 and 11 AM on a Wednesday morning. You will be consulted about your preference regarding time and date. Appointments are typically made at least one month in advance.

How do I contact the Adult PKU Team?

Call Janet Garretson, MSW at 206-598-2444. She is in her office on Monday, Wednesday, and Thursday. Judy Brown, RD, CD can be reached at 206-598-6361. If you need a toll-free number, please leave a message for Janet Garretson, MSW at 1-877-685-3015.



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195

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

Once I complete the Transition to the Adult Clinic, how often will I have clinic appointments?

Appointments in the Adult PKU Clinic are scheduled for once a year. Remember that blood samples are still requested on a monthly basis. If you have questions or need advice appointments can be scheduled with Janet Garretson, MSW or Judy Brown, MS, RD at a mutually convenient time.

What if I am in college and living away from Seattle?

Talk with Janet Garretson, MSW and arrange your appointment for when you are in Seattle between terms or in the summer.

Where do I send my blood samples?

There is no change in the system for processing blood samples. You may send your filter paper blood sample to the newborn-screening laboratory. See the **Resources** section for details.

How do I order my formula?

Persons enrolled in the Adult PKU Clinic are asked to sign a contract that requires blood samples to be submitted on a regular basis as a requirement for obtaining a prescription for formula. Once the prescription is in place, please call Jan Garretson, MSW to order your formula.

If you have submitted a blood sample within the previous 4 to 6 weeks, she will arrange with the Department of Health to have formula shipped to you. **Please keep track of your supply of formula so you place your order for additional formula before you are using the last case of formula.**

What is the Adult PKU Clinic contract?

The Adult PKU Clinic contract is a document that outlines the responsibilities of both parties, that is, the person with PKU and the PKU Clinic Team. The contract is meant to clarify mutual responsibilities: yours and those of the PKU Clinic team.

Clear communication between you and the PKU Clinic team is essential as you go through many changes in your life. These changes, such as housing, employment, education, insurance, travel, marriage, and family planning are all opportunities and challenges for you. The Adult PKU team will work with you to help you be sure that you have the resources to maintain your blood phe levels in the desired range.



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195

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

CLINIC VISITS AND BLOOD PHE LEVELS

Use this table to keep track of your clinic visits and blood phenylalanine levels.

	Phe Level	Comments
Transition Visit #1 – Date: <u>Ex: 3/25/03</u> Food record: <input checked="" type="checkbox"/> yes <input type="checkbox"/> no	8.2	Had a cold the week before clinic
Follow-up blood draw – Date: <u>4/22/03</u>	4.6	
Follow-up blood draw – Date: <u>5/20/03</u>	5.2	
Transition Visit #1 – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Transition Visit #2 – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Transition Visit #3 – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Transition Visit #4 – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Transition Visit #5 – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		



University of Washington PKU Clinic
 CHDD - Box 357920, Seattle, WA 98195

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

	Phe Level	Comments

Transition Visit #6 Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Transition Visit #7 – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Transition Visit #8 – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		



University of Washington PKU Clinic
 CHDD - Box 357920, Seattle, WA 98195

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

CLINIC VISITS AND BLOOD PHE LEVELS

Use this table to keep track of your clinic visits and blood phenylalanine levels.

	Phe Level	Comments
Annual PKU Clinic Visit – Date: _____ Food record: <input type="checkbox"/> yes <input type="checkbox"/> no		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Follow-up blood draw – Date: _____		
Other Medical Appointments / Labs		



University of Washington PKU Clinic
 CHDD - Box 357920, Seattle, WA 98195

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

HEALTH CARE PROVIDER INFORMATION

PKU Clinic: University of Washington PKU Clinic

Phone: (206) 598-1800 or toll-free 1-877-685-3015 Fax: (206) 598-1915

Address: Box 357920, Seattle, WA 98195

Physician(s): _____

Nutritionist(s): _____

Social Worker(s): _____

Program Coordinator(s): _____

Genetic Counselor(s): _____

Primary Care Provider: _____

Phone: _____ Fax: _____

Address: _____

Community Hospital: _____

Medical Record Number: _____

Phone: _____ Fax: _____

Address: _____

Pharmacy: _____

Phone: _____ Fax: _____

Address: _____

Dentist: _____

Phone: _____ Fax: _____

Address: _____

Other: _____

Phone: _____ Fax: _____

Address: _____



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195

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

INSURANCE INFORMATION

Insurance Company Name: _____

Policy Number: _____

Contact Person/Title: _____

Address: _____

Phone: _____ Fax: _____

Insurance Company Name: _____

Policy Number: _____

Contact Person/Title: _____

Address: _____

Phone: _____ Fax: _____

Other

Contact Person/Title: _____

Address: _____

Phone: _____



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195

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

IMMUNIZATION RECORD

Use this form to record the immunizations you received when you were an infant and child. Also use it to keep track of immunizations you received as an adult. The information sheet on the next page describes how often you should receive the adult vaccinations (e.g., tetanus/diphtheria, influenza, varicella).

	DTP	Polio	Measles	Hib	Adult	Hepatitis B	Varicella (chicken pox)
			MUMPS	DISEASE	TETANUS		
			RUBELLA				
DATE							
DATE							
DATE							
DATE							
DATE							
DATE							
DATE							
DATE							
DATE							
DATE							
DATE							
	DATE	DATE	DATE	DATE	DATE	DATE	DATE
Flu Vaccine							
Pneumococcal Vaccine							
Meningococcal Vaccine							



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195

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

Recommended Adult Immunization Schedule – United States, 2009

MMWRTM
QuickGuide

Weekly

January 9, 2009 / Vol. 57 / No. 53

The Advisory Committee on Immunization Practices (ACIP) annually reviews the recommended Adult Immunization Schedule to ensure that the schedule reflects current recommendations for the licensed vaccines. In October 2008, ACIP approved the Adult Immunization Schedule for 2009. No new vaccines were added to the schedule; however, several indications were added to the pneumococcal polysaccharide vaccine footnote, clarifications were made to the footnotes for human papillomavirus, varicella, and meningococcal vaccines, and schedule information was added to the hepatitis A and hepatitis B vaccine footnotes.

Additional information is available as follows: schedule (in English and Spanish) at <http://www.cdc.gov/vaccines/recs/schedules/adult-schedule.htm>; adult vaccination at <http://www.cdc.gov/vaccines/default.htm>; ACIP statements for specific vaccines at <http://www.cdc.gov/vaccine/pubs/acip-list.htm>; and reporting adverse events at <http://www.vaers.hhs.gov> or by telephone, 800-822-7967.

Changes for 2009

Format Changes (Figures 1 and 2)

To make the figures easier to understand, several formatting changes were implemented to both the age group–based schedule and the medical and other indications schedule. The changes include 1) increasing the number of age groups; 2) deleting the hatched yellow bar for tetanus, diphtheria, pertussis (Td/Tdap) vaccine while adding explanatory text to the Td/Tdap bar; 3) simplifying the figures by removing schedule text from the vaccine bars; 4) revising the order of the vaccines to more appropriately group the vaccines, and 5) adding a legend box to clarify the meaning of blank spaces in the table.

Footnote (Figures 1 and 2)

- The human papillomavirus (HPV) footnote (#2) has language added to indicate that health-care personnel are not at increased risk because of occupational exposure, but they should be vaccinated consistent with age-based recommendations. Also, text has been added to indicate that vaccination with HPV may begin at age 9 years.
- The varicella footnote (#3) has language added to clarify that adults who previously received only 1 dose of vaccine should receive a second dose.
- Asthma and cigarette smoking have been added as indications for pneumococcal polysaccharide vaccination (#7). Also, text has been added to clarify vaccine use in Alaska Natives and American Indians.
- The Hepatitis A footnote (#9) has additional schedule information for the 4-dose combined hepatitis A/hepatitis B vaccine.
- The Hepatitis B footnote (#10) has additional schedule information for the 4-dose combined hepatitis A/hepatitis B vaccine, and a clarification of schedule information for special formulation indications has been added.
- The meningococcal vaccine footnote (#11) clarifies that the revaccination interval is 5 years.

The Recommended Adult Immunization Schedule has been approved by the Advisory Committee on Immunization Practices, the American Academy of Family Physicians, the American College of Obstetricians and Gynecologists, and the American College of Physicians.

Suggested citation: Centers for Disease Control and Prevention. Recommended adult immunization schedule—United States, 2009. *MMWR* 2008;57(53).

FIGURE 1. Recommended adult immunization schedule by vaccine and age group — United States, 2009

VACCINE ▼	AGE GROUP ►	19–26 years	27–49 years	50–59 years	60–64 years	≥65 years
Tetanus, diphtheria, pertussis (Td/Tdap) ^{1,*}		Substitute 1-time dose of Tdap for Td booster; then boost with Td every 10 yr				Td booster every 10 yrs
Human papillomavirus (HPV) ^{2,*}		3 doses (females)				
Varicella ^{3,*}		2 doses				
Zoster ⁴					1 dose	
Measles, mumps, rubella (MMR) ^{5,*}		1 or 2 doses		1 dose		
Influenza ^{6,*}		1 dose annually				
Pneumococcal (polysaccharide) ^{7,8}		1 or 2 doses				1 dose
Hepatitis A ^{9,*}		2 doses				
Hepatitis B ^{10,*}		3 doses				
Meningococcal ^{11,*}		1 or more doses				

*Covered by the Vaccine Injury Compensation Program.

 For all persons in this category who meet the age requirements and who lack evidence of immunity (e.g., lack documentation of vaccination or have no evidence of prior infection)

 Recommended if some other risk factor is present (e.g., on the basis of medical, occupational, lifestyle, or other indications)

 No recommendation

NOTE: The above recommendations must be read along with the footnotes on pages Q2–Q4 of this schedule.

1. Tetanus, diphtheria, and acellular pertussis (Td/Tdap) vaccination

Tdap should replace a single dose of Td for adults aged 19 through 64 years who have not received a dose of Tdap previously

Adults with uncertain or incomplete history of primary vaccination series with tetanus and diphtheria toxoid-containing vaccines should begin or complete a primary vaccination series. A primary series for adults is 3 doses of tetanus and diphtheria toxoid-containing vaccines; administer the first 2 doses at least 4 weeks apart and the third dose 6–12 months after the second. However, Tdap can substitute for any one of the doses of Td in the 3-dose primary series. The booster dose of tetanus and diphtheria toxoid-containing vaccine should be administered to adults who have completed a primary series and if the last vaccination was received 10 or more years previously. Tdap or Td vaccine may be used, as indicated.

If a woman is pregnant and received the last Td vaccination 10 or more years previously, administer Td during the second or third trimester. If the woman received the last Td vaccination less than 10 years previously, administer Tdap during the immediate postpartum period. A dose of Tdap is recommended for postpartum women, close contacts of infants aged less than 12 months, and all health-care personnel with direct patient contact if they have not previously received Tdap. An interval as short as 2 years from the last Td is suggested; shorter intervals can be used. Td may be deferred during pregnancy and Tdap substituted in the immediate postpartum period, or Tdap may be administered instead of Td to a pregnant woman after an informed discussion with the woman.

Consult the ACIP statement for recommendations for administering Td as prophylaxis in wound management.

2. Human papillomavirus (HPV) vaccination

HPV vaccination is recommended for all females aged 11 through 26 years (and may begin at age 9 years) who have not completed the vaccine series. History of genital warts, abnormal Papanicolaou test, or positive HPV DNA test is not evidence of prior infection with all vaccine HPV types; HPV vaccination is recommended for persons with such histories.

Ideally, vaccine should be administered before potential exposure to HPV through sexual activity; however, females who are sexually active should still be vaccinated consistent with age-based recommendations. Sexually active females who have not been infected with any of the four HPV vaccine types receive the full benefit of the vaccination. Vaccination is less beneficial for females who have already been infected with one or more of the HPV vaccine types.

A complete series consists of 3 doses. The second dose should be administered 2 months after the first dose; the third dose should be administered 6 months after the first dose.

HPV vaccination is not specifically recommended for females with the medical indications described in Figure 2, “Vaccines that might be indicated for adults based on medical and other indications.” Because HPV vaccine is not a live-virus vaccine, it may be administered to persons with the medical indications described in Figure 2. However, the immune response and vaccine efficacy might be less for persons with the medical indications described in Figure 2 than in persons who do not have the medical indications described or who are immunocompetent. Health-care personnel are not at increased risk because of occupational exposure, and should be vaccinated consistent with age-based recommendations.

3. Varicella vaccination

All adults without evidence of immunity to varicella should receive 2 doses of single-antigen varicella vaccine if not previously vaccinated or the second dose if they have received only one dose, unless they have a medical contraindication. Special consideration should be given to those who 1) have close contact with persons at high risk for severe disease (e.g., health-care personnel and family contacts of persons with immunocompromising conditions) or 2) are at high risk for exposure or transmission (e.g., teachers; child care employees; residents and staff members of institutional settings, including correctional institutions; college students; military personnel; adolescents and adults living in households with children; nonpregnant women of childbearing age; and international travelers).

Evidence of immunity to varicella in adults includes any of the following: 1) documentation of 2 doses of varicella vaccine at least 4 weeks apart; 2) U.S.-born before 1980 (although for health-care personnel and pregnant women, birth before 1980 should not be considered evidence of immunity); 3) history of varicella based on diagnosis or verification of varicella by a health-care provider (for a patient reporting a history of or presenting with an atypical case, a mild case, or both, health-care providers should seek either an epidemiologic link to a typical varicella case or to a laboratory-confirmed case or evidence of laboratory confirmation, if it was performed at the time of acute disease); 4) history of herpes zoster based on health-care provider diagnosis or verification of herpes zoster by a health-care provider; or 5) laboratory evidence of immunity or laboratory confirmation of disease.

Pregnant women should be assessed for evidence of varicella immunity. Women who do not have evidence of immunity should receive the first dose

FIGURE 2. Vaccines that might be indicated for adults based on medical and other indications — United States, 2009

VACCINE ▼	INDICATION ►	Pregnancy	Immuno-compromising conditions (excluding human immunodeficiency virus [HIV]) ¹³	HIV infection ^{3,12,13} CD4+ T lymphocyte count		Diabetes, heart disease, chronic lung disease, chronic alcoholism	Asplenia ¹² (including elective splenectomy and terminal complement deficiencies)	Chronic liver disease	Kidney failure, end-stage renal disease, receipt of hemodialysis	Health-care personnel	
				<200 cells/μL	≥200 cells/μL						
Tetanus, diphtheria, pertussis (Td/Tdap) ^{1,*}		Td	Substitute 1-time dose of Tdap for Td booster; then boost with Td every 10 yrs								
Human papillomavirus (HPV) ^{2,*}			3 doses for females through age 26 yrs								
Varicella ^{3,*}		Contraindicated		2 doses							
Zoster ⁴		Contraindicated		1 dose							
Measles, mumps, rubella (MMR) ^{5,*}		Contraindicated		1 or 2 doses							
Influenza ^{6,*}			1 dose TIV annually								1 dose TIV or LAIV annually
Pneumococcal (polysaccharide) ^{7,8}			1 or 2 doses								
Hepatitis A ^{9,*}			2 doses								
Hepatitis B ^{10,*}			3 doses								
Meningococcal ^{11,*}			1 or more doses								

* Covered by the Vaccine Injury Compensation Program.

For all persons in this category who meet the age requirements and who lack evidence of immunity (e.g., lack documentation of vaccination or have no evidence of prior infection)
Recommended if some other risk factor is present (e.g., on the basis of medical, occupational, lifestyle, or other indications)
No recommendation

NOTE: The above recommendations must be read along with the footnotes on pages Q2–Q4 of this schedule.

of varicella vaccine upon completion or termination of pregnancy and before discharge from the health-care facility. The second dose should be administered 4–8 weeks after the first dose.

4. Herpes zoster vaccination

A single dose of zoster vaccine is recommended for adults aged 60 years and older regardless of whether they report a prior episode of herpes zoster. Persons with chronic medical conditions may be vaccinated unless their condition constitutes a contraindication.

5. Measles, mumps, rubella (MMR) vaccination

Measles component: Adults born before 1957 generally are considered immune to measles. Adults born during or after 1957 should receive 1 or more doses of MMR unless they have a medical contraindication, documentation of 1 or more doses, history of measles based on health-care provider diagnosis, or laboratory evidence of immunity.

A second dose of MMR is recommended for adults who 1) have been recently exposed to measles or are in an outbreak setting; 2) have been vaccinated previously with killed measles vaccine; 3) have been vaccinated with an unknown type of measles vaccine during 1963–1967; 4) are students in postsecondary educational institutions; 5) work in a health-care facility; or 6) plan to travel internationally.

Mumps component: Adults born before 1957 generally are considered immune to mumps. Adults born during or after 1957 should receive 1 dose of MMR unless they have a medical contraindication, history of mumps based on health-care provider diagnosis, or laboratory evidence of immunity.

A second dose of MMR is recommended for adults who 1) live in a community experiencing a mumps outbreak and are in an affected age group; 2) are students in postsecondary educational institutions; 3) work in a health-care facility; or 4) plan to travel internationally. For unvaccinated health-care personnel born before 1957 who do not have other evidence of mumps immunity, administering 1 dose on a routine basis should be considered and administering a second dose during an outbreak should be strongly considered.

Rubella component: 1 dose of MMR vaccine is recommended for women whose rubella vaccination history is unreliable or who lack laboratory evidence of immunity. For women of childbearing age, regardless of birth year, rubella

immunity should be determined and women should be counseled regarding congenital rubella syndrome. Women who do not have evidence of immunity should receive MMR vaccine upon completion or termination of pregnancy and before discharge from the health-care facility.

6. Influenza vaccination

Medical indications: Chronic disorders of the cardiovascular or pulmonary systems, including asthma; chronic metabolic diseases, including diabetes mellitus, renal or hepatic dysfunction, hemoglobinopathies, or immunocompromising conditions (including immunocompromising conditions caused by medications or human immunodeficiency virus [HIV]); any condition that compromises respiratory function or the handling of respiratory secretions or that can increase the risk of aspiration (e.g., cognitive dysfunction, spinal cord injury, or seizure disorder or other neuromuscular disorder); and pregnancy during the influenza season. No data exist on the risk for severe or complicated influenza disease among persons with asplenia; however, influenza is a risk factor for secondary bacterial infections that can cause severe disease among persons with asplenia.

Occupational indications: All health-care personnel, including those employed by long-term care and assisted-living facilities, and caregivers of children less than 5 years old.

Other indications: Residents of nursing homes and other long-term care and assisted-living facilities; persons likely to transmit influenza to persons at high risk (e.g., in-home household contacts and caregivers of children aged less than 5 years old, persons 65 years old and older and persons of all ages with high-risk condition[s]); and anyone who would like to decrease their risk of getting influenza. Healthy, nonpregnant adults aged less than 50 years without high-risk medical conditions who are not contacts of severely immunocompromised persons in special care units can receive either intranasally administered live, attenuated influenza vaccine (FluMist[®]) or inactivated vaccine. Other persons should receive the inactivated vaccine.

7. Pneumococcal polysaccharide (PPSV) vaccination

Medical indications: Chronic lung disease (including asthma); chronic cardiovascular diseases; diabetes mellitus; chronic liver diseases, cirrhosis; chronic alcoholism, chronic renal failure or nephrotic syndrome; functional or anatomic asplenia (e.g., sickle cell disease or splenectomy [if elective splenectomy

is planned, vaccinate at least 2 weeks before surgery]); immunocompromising conditions; and cochlear implants and cerebrospinal fluid leaks. Vaccinate as close to HIV diagnosis as possible.

Other indications: Residents of nursing homes or other long-term care facilities and persons who smoke cigarettes. Routine use of PPSV is not recommended for Alaska Native or American Indian persons younger than 65 years unless they have underlying medical conditions that are PPSV indications. However, public health authorities may consider recommending PPSV for Alaska Natives and American Indians aged 50 through 64 years who are living in areas in which the risk of invasive pneumococcal disease is increased.

8. Revaccination with PPSV

One-time revaccination after 5 years is recommended for persons with chronic renal failure or nephrotic syndrome; functional or anatomic asplenia (e.g., sickle cell disease or splenectomy); and for persons with immunocompromising conditions. For persons aged 65 years and older, one-time revaccination if they were vaccinated 5 or more years previously and were aged less than 65 years at the time of primary vaccination.

9. Hepatitis A vaccination

Medical indications: Persons with chronic liver disease and persons who receive clotting factor concentrates.

Behavioral indications: Men who have sex with men and persons who use illegal drugs.

Occupational indications: Persons working with hepatitis A virus (HAV)-infected primates or with HAV in a research laboratory setting.

Other indications: Persons traveling to or working in countries that have high or intermediate endemicity of hepatitis A (a list of countries is available at <http://www.cdc.gov/travel/content/diseases.aspx>) and any person seeking protection from HAV infection.

Single-antigen vaccine formulations should be administered in a 2-dose schedule at either 0 and 6–12 months (Havrix[®]), or 0 and 6–18 months (Vaqta[®]). If the combined hepatitis A and hepatitis B vaccine (Twinrix[®]) is used, administer 3 doses at 0, 1, and 6 months; alternatively, a 4-dose schedule, administered on days 0, 7, and 21 to 30 followed by a booster dose at month 12 may be used.

10. Hepatitis B vaccination

Medical indications: Persons with end-stage renal disease, including patients receiving hemodialysis; persons with HIV infection; and persons with chronic liver disease.

Occupational indications: Health-care personnel and public-safety workers who are exposed to blood or other potentially infectious body fluids.

Behavioral indications: Sexually active persons who are not in a long-term, mutually monogamous relationship (e.g., persons with more than 1 sex partner during the previous 6 months); persons seeking evaluation or treatment for a sexually transmitted disease (STD); current or recent injection-drug users; and men who have sex with men.

Other indications: Household contacts and sex partners of persons with chronic hepatitis B virus (HBV) infection; clients and staff members of institutions for persons with developmental disabilities; international travelers to countries with high or intermediate prevalence of chronic HBV infection (a list of countries

is available at <http://wwwn.cdc.gov/travel/content/diseases.aspx>); and any adult seeking protection from HBV infection.

Hepatitis B vaccination is recommended for all adults in the following settings: STD treatment facilities; HIV testing and treatment facilities; facilities providing drug-abuse treatment and prevention services; health-care settings targeting services to injection-drug users or men who have sex with men; correctional facilities; end-stage renal disease programs and facilities for chronic hemodialysis patients; and institutions and nonresidential daycare facilities for persons with developmental disabilities.

If the combined hepatitis A and hepatitis B vaccine (Twinrix[®]) is used, administer 3 doses at 0, 1, and 6 months; alternatively, a 4-dose schedule, administered on days 0, 7, and 21 to 30 followed by a booster dose at month 12 may be used.

Special formulation indications: For adult patients receiving hemodialysis or with other immunocompromising conditions, 1 dose of 40 µg/mL (Recombivax HB[®]) administered on a 3-dose schedule or 2 doses of 20 µg/mL (Engerix-B[®]) administered simultaneously on a 4-dose schedule at 0, 1, 2 and 6 months.

11. Meningococcal vaccination

Medical indications: Adults with anatomic or functional asplenia, or terminal complement component deficiencies.

Other indications: First-year college students living in dormitories; microbiologists routinely exposed to isolates of *Neisseria meningitidis*; military recruits; and persons who travel to or live in countries in which meningococcal disease is hyperendemic or epidemic (e.g., the “meningitis belt” of sub-Saharan Africa during the dry season [December–June]), particularly if their contact with local populations will be prolonged. Vaccination is required by the government of Saudi Arabia for all travelers to Mecca during the annual Hajj.

Meningococcal conjugate vaccine (MCV) is preferred for adults with any of the preceding indications who are aged 55 years or younger, although meningococcal polysaccharide vaccine (MPSV) is an acceptable alternative. Revaccination with MCV after 5 years might be indicated for adults previously vaccinated with MPSV who remain at increased risk for infection (e.g., persons residing in areas in which disease is epidemic).

12. Selected conditions for which *Haemophilus influenzae* type b (Hib) vaccine may be used

Hib vaccine generally is not recommended for persons aged 5 years and older. No efficacy data are available on which to base a recommendation concerning use of Hib vaccine for older children and adults. However, studies suggest good immunogenicity in patients who have sickle cell disease, leukemia, or HIV infection or who have had a splenectomy; administering 1 dose of vaccine to these patients is not contraindicated.

13. Immunocompromising conditions

Inactivated vaccines generally are acceptable (e.g., pneumococcal, meningococcal, and influenza [trivalent inactivated influenza vaccine]) and live vaccines generally are avoided in persons with immune deficiencies or immunocompromising conditions. Information on specific conditions is available at <http://www.cdc.gov/vaccines/pubs/acip-list.htm>.

These schedules indicate the recommended age groups and medical indications for which administration of currently licensed vaccines is commonly indicated for adults ages 19 years and older, as of January 1, 2009. Licensed combination vaccines may be used whenever any components of the combination are indicated and when the vaccine's other components are not contraindicated. For detailed recommendations on all vaccines, including those used primarily for travelers or that are issued during the year, consult the manufacturers' package inserts and the complete statements from the Advisory Committee on Immunization Practices (<http://www.cdc.gov/vaccines/pubs/acip-list.htm>).

Report all clinically significant postvaccination reactions to the Vaccine Adverse Event Reporting System (VAERS). Reporting forms and instructions on filing a VAERS report are available at <http://www.vaers.hhs.gov> or by telephone, 800-822-7967.

Information on how to file a Vaccine Injury Compensation Program claim is available at <http://www.hrsa.gov/vaccinecompensation> or by telephone, 800-338-2382. To file a claim for vaccine injury, contact the U.S. Court of Federal Claims, 717 Madison Place, N.W., Washington, D.C. 20005; telephone, 202-357-6400.

Additional information about the vaccines in this schedule, extent of available data, and contraindications for vaccination is also available at <http://www.cdc.gov/vaccines> or from the CDC-INFO Contact Center at 800-CDC-INFO (800-232-4636) in English and Spanish, 24 hours a day, 7 days a week.

Use of trade names and commercial sources is for identification only and does not imply endorsement by the U.S. Department of Health and Human Services.

ANTICIPATORY GUIDANCE FOR THE ADOLESCENT

In addition to providing anticipatory guidance, many health professionals give families handouts at an appropriate reading level or a videotape that they can review or study at home.

Promotion of Healthy and Safe Habits

Try to get 8 hours of sleep a day.

Engage in moderately strenuous to vigorous physical activity for 30 to 60 minutes at least three times a week. Encourage friends and family members to be physically active.

Check with the health professional before increasing physical activity. Ask the health professional or coach about athletic conditioning, weight training, fluids, and weight gain or loss.

Practice time management skills.

Injury and Violence Prevention

Always wear a safety belt when driving or riding in the car. If you are driving, insist that your passengers wear safety belts.

Follow the speed limit and drive responsibly.

Concentrate when driving and avoid distractions (e.g., playing loud music, eating, talking on the phone when driving).

Do not drink alcohol, especially while driving, swimming, boating, or operating farm equipment or other machinery. Plan to ride with a designated driver or to call for a ride if drinking.

Learn how to swim (if you haven't already learned).

Learn first aid and CPR.

Reduce your risk of developing skin cancer by limiting time in the sun and applying sunscreen (SPF 15 or higher) before going outside. Avoid tanning salons.

Test smoke alarms in your home to be sure they work properly. Change batteries yearly.

Know what to do in case of a fire or other emergency. Review fire safety plans at home.

Wear protective gear (e.g., eye protection, mouth guard, helmet, knee and elbow pads) for sports and other physical activities such as in-line skating.

Always wear a helmet when riding a bike, motorcycle, or all-terrain vehicle. However, ATVs and motorcycles are dangerous, even with a helmet.

Wear appropriate protective gear at work and follow job safety procedures.

Avoid high noise levels, especially when using earphones.

Do not carry or use a weapon of any kind.

Develop skills in conflict resolution, negotiation, and dealing with anger constructively.

Learn techniques to protect yourself from physical, emotional, and sexual abuse or rape.

Seek help if you are physically or sexually abused or fear that you are in danger.

Mental Health

Take on new challenges that will increase your self-confidence.

Continue to develop your sense of identity, clarifying your values and beliefs.

Accept who you are and enjoy both the child and adult in you.

Trust your own feelings and listen to feedback from trusted friends and adults.

Seek help if you often feel angry, depressed, or hopeless. Resources include counselors and MDs.

Learn how to deal with stress.

Set reasonable but challenging goals.

Understand the importance of your spiritual needs and try to fulfill them.

Nutrition

Choose, purchase, and prepare a variety of healthy foods.

Eat three nutritious meals a day at regularly scheduled times; breakfast is especially important.

Select a nutritious lunch from the cafeteria at your school or workplace, or pack a balanced lunch.

Enjoy meals in a pleasant environment with your family, friends, or roommates.

Choose plenty of fruits and vegetables; breads, cereals, and other low-protein grain products; and foods prepared with little or no fat. Use a medical food/formula to provide energy, protein, calcium, iron, and other vitamins and minerals.

Choose nutritious snacks rich in complex carbohydrates. Limit high-fat or low-nutrient foods and beverages such as candy, chips, or soft drinks.

Achieve and maintain a healthy weight. Manage weight through appropriate eating habits and regular physical activity.

Oral Health

Brush your teeth twice a day with a pea-size amount of fluoridated toothpaste, and floss between your teeth daily.

Ask the health professional or your dentist any questions you have about how to handle dental emergencies, especially the loss or fracture of a tooth.

Schedule a dental appointment every 6 months or as indicated, based on your individual needs or susceptibility to disease.

As your third permanent molars (wisdom teeth) erupt, be sure that your dentist evaluates them for placement of dental sealants. Some wisdom teeth are impacted and may need to be extracted.

Do not smoke or use chewing tobacco.

Sexuality^b

Talk with the health professional about sexual maturity; contraception; prevention of sexually transmitted diseases; gay, lesbian, and bisexual issues; celibacy; and other issues related to sexuality. Discuss any questions you have.

If you are confused or concerned about your sexual feelings (for the same sex or opposite sex), talk with the health professional or a trusted adult.

Having sex should be a well-thought-out decision. Delay having sex until you and your partner are mature enough to assume responsibility for sexual relations. Share your feelings about sexuality with your partner.

Abstaining from sexual intercourse is the safest way to prevent pregnancy and sexually transmitted diseases, including HIV/AIDS.

Learn about ways to resist sexual pressures.

If you are sexually active, discuss contraceptive methods and STD prevention with the health professional and your partner. Learn about and practice safer sex.

Limit the number of partners, and use latex condoms and other barriers correctly.

Prevention of Substance Use/Abuse

Do not smoke, use smokeless tobacco, drink alcohol, or use drugs, diet pills, or steroids. Do not become involved in selling drugs.

If you smoke, talk with the health professional about how to stop smoking.

If you use drugs or alcohol, talk with the health professional and ask for help (e.g., a substance abuse treatment program).

Support friends who choose not to use tobacco, alcohol, drugs, steroids, or diet pills.

Promotion of Social Competence

Continue to maintain strong family relationships.

Participate in social activities, community groups, or team sports.

Develop satisfying peer and sibling relationships.

Identify social support systems.

Use peer refusal skills to handle negative peer pressure.

Continue your progress in achieving independence, making mature decisions, and anticipating the consequences of your behavior.

Promotion of School/Vocational Achievement

Identify talents and interests that you want to pursue for a career or for personal enrichment.

Plan for the future (e.g., college, graduate school, vocational training, the military, job/career).

Promotion of Responsibility

Respect the rights and needs of others.

Serve as a positive role model.

Talk with the health professional about your plans for the future (e.g., employment, education, housing, marriage).

Learn about how you can take on new responsibility in your family, peer group, and community.

Learn new skills (e.g., lifesaving, peer counseling) that can help your friends, family, or community.

Talk with the health professional about taking responsibility for your own health and becoming fully informed about preventive health services.

Ask for assistance with entering the adult health care system if your care has been provided by a pediatrician or pediatric nurse practitioner.

Discuss your future reproductive plans with the health professional, including your PKU doctor. Ask about the things you can do before conceiving that will improve your chances of having a healthy baby.

If You Are Thinking of Having a Baby...

Consult with your PKU doctor about blood levels before conception and with your PKU nutritionist to make sure that your formula and food pattern will be adequate.

Talk with your partner and the health professional about the physical, emotional, and financial responsibilities involved.

Take a folic acid supplement daily before and during pregnancy, and eat foods fortified with folic acid (e.g., fortified breakfast cereals and enriched breads, rice, and pasta).¹⁴

Avoid using tobacco, alcohol, and other drugs before and during pregnancy to avoid harming your unborn baby.

Engage in physical activity before and during pregnancy to maintain healthy body weight and muscle tone.

Consider seeking genetic counseling (if indicated).

Promotion of Community Interactions

If you need financial assistance for health care expenses, ask about resources or referrals to the state Medicaid program or other state medical assistance programs.

Ask about resources or referrals for food, housing, or transportation if needed.

Participate in social, religious, cultural, volunteer, or recreational organizations or activities.

Advocate for community programs (recreational, athletic, artistic, and educational activities).

Talk with family and friends about current events and community responsibilities such as voting and recycling.

Explore your cultural heritage and learn about other cultures. Participate in activities that reflect cultural diversity.

Find out what you can do about community problems such as unemployment, lack of housing, violence, crime, environmental issues, or inadequate public services.

Join community campaigns to prevent substance abuse. Advocate for smoke-free environments in your school, workplace, and/or community.

Ask about health programs and services in your school or workplace.

ANTICIPATORY GUIDANCE FOR THE PARENT(S)

In addition to providing anticipatory guidance, many health professionals give families handouts at an appropriate reading level or a videotape that they can review or study at home.

Encourage your adolescent's or young adult's independent decision-making.

Spend time with your adolescent or young adult.

Respect your adolescent's or young adult's need for privacy.

Enhance your adolescent's or young adult's self-esteem by showing affection, praising positive behavior, and recognizing efforts and achievements.

Establish joint expectations with your adolescent or young adult regarding family rules and responsibilities.

Minimize criticism and avoid nagging, derogatory comments and other belittling or demeaning messages.

Talk with your adolescent or young adult about her plans for independent living (money management, health care, food preparation, education, job or career).

Talk with the health professional about your own preventive and health-promoting practices (e.g., avoiding tobacco, eating nutritiously, being physically active, doing breast self-exams or testicular self-exams).

Model safe driving practices (e.g., avoiding alcohol, using safety belts) and discuss family rules about driving.

Help your adolescent or young adult understand that driving is a privilege and a responsibility.

Insist that your adolescent or young adult and all passengers wear safety belts.

Remind your adolescent or young adult to concentrate when driving and to avoid distractions (e.g., playing loud music, eating, talking on the phone when driving).

Discuss with your adolescent or young adult the dangers of drinking and driving. Write and sign a "no drinking and driving" contract with your adolescent.

Urge your adolescent or young adult to always call you for a ride if he or another driver has been drinking. Be sure she understands that you will pick her up at any time if she has been drinking.

Advise your adolescent or young adult to make arrangements for a designated driver if she plans to drink.

Advocate for and participate in alcohol-free community events (e.g., proms, graduation parties).

Resources

- To order formula call 206-361-2917, or toll-free 866-660-9050
- To schedule an appointment at the Adult PKU clinic call Janet Garretson, MSW at 206-598-2444, or toll-free 877-685-3015
- To order filter papers call Janet Garretson, MSW at 206-598-2444, or toll-free 877-685-3015
- To order small amounts of low protein food call the UW PKU Clinic Food Co-op at 206-598-1800

Or order from companies:

- **Dietary Specialties** 1-888-menu123 or www.dietspec.com
 - **Med-Diet** 1-800-Med-Diet or <http://med-diet.com>
 - **SHS North America** 1-800-482-7845 or www.shsna.com
 - **Ener-G Foods, Inc.** 1-800-331-5222 or www.ener-g.com
 - **Cambrooke Foods** 1-866-4-LOW PRO or www.cambrookefoods.com
- To find out about Washington Basic Health and the eligibility criteria access online at www.basichealth.hca.wa.gov/
 - If you have insurance questions contact your insurance company or the Human Resources/Benefits office _____
 - If you need to ask a nurse a question contact the hotline through your health insurance company or local hospital _____
 - Access the National PKU News online at www.pkunews.org
 - Access information on the UW PKU Clinic online at: depts.washington.edu/pku Two books to help with cooking and calculating phe:
 - Low Protein Cookery for PKU* by V.E. Schuett.
Available from the National PKU News Web site under "Diet-Related Info."
Ordering information: <http://205.178.182.34/diet/pkord.htm>
 - Low Protein Food List for PKU* by V.E. Schuett.
Available from the National PKU News Web site under "Diet-Related Info."
Ordering information: <http://205.178.182.34/diet/pkord.htm>



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195

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

Assessment of PKU Adolescent Transition Curriculum

Session 8.

Objective: At this visit you will have the opportunity to finalize a plan for your independent living, complete the formula payment problem solving activity, and visit the Adult PKU Clinic.

Post Session Objective: Each participant will be able to explain the basic components of a plan for independent living and complete the problem solving activity.

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

1)

2)

3)

II. Why is it so important to keep track of your health insurance and provisions for formula payment?

III. Do you have any unanswered questions about transition to the Adult PKU Clinic?



University of Washington PKU Clinic
CHDD - Box 357920, Seattle, WA 98195

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