PKU CARE PLAN

Care Plan Notebook: A place to keep and organize your information to assist you (or family) in caring for child/adult with a genetic/metabolic disorder.
This can be as detailed or brief as you like, just so it works for you.

Example of PKU Care Plan:

I used common elements of care plans as our "tabs" for the notebook (from our 1/10 info)

I have built the notebook using selections from the AAP and Medical Home info web site and included some examples from our clinic. (if we were to use this on our Region 4 web site I think we would have to check with AAP since their terms of use say for single use download.)

I will include ideas for sections and an example of a form obtained from the Medical Home Build a Care Notebook site.

PKU Care Notebook

Tab 1 Child and Family Information (This is combination of Demographic info and About our family sections)
Insert Family Information sheet here

Tab 2 Services and Supports
Insert Supplies List UT here (for PKU formula supplier information and tracking if receive formula from private vendor or home care agency. This will vary with Insurance or program you are on.)
You could also include contact numbers and e-mail info if you order directly from supplier.—Your Clinic may have these numbers for you.

Tab 3 Health Information (this is probably the biggest section and you may need "sub tabs' or pocket pages for this section

Insert Health Care Providers List and Immunization and Allergies R and Medication Log Lists here

"sub tab on PKU information:
Include information about PKU, PKU resources such as web sites, state parent groups, and other information you might like to keep about PKU here

sub section on diet: include how to contact dietitian

Insert Food Intake Diary-IllCRE , Diet Tracking form WA and/or your Clinic's Food Record Lists

Sample formula recipe sheet (or what your Clinic uses) to help you keep track of Of your formula recipe

Sub section on Labs:

Include information from you clinic on process of Phe monitoring procedure and Collection

Insert Lab Work/ Test/ Procedures sheet here
Insert Dr. Visit Tracking sheet OH here

Tab 4 Developmental Information:
Include information related to child development that you wish to note or track here.

Tab 5 Education:
Include any education information you want to keep here
For PKU special diet may want to include copies of letters to school or daycare about this which you Clinic may have provided.

Tab 6 Insurance :
Insert Insurance Funding Information sheet here
Insert Medical Bill Tracking Form here

Tab 7 Goals/ Plan of Action
Insert Transitions ND list here
Some goals to include for PKU child by age include:
0-1 year Parents/Family learn about PKU, how to mix formula, transitions to foods and tracking diet/Phe. Know when and how to contact Specialist and emergency contact information.

2-6 years Continue record keeping and monitoring levels as recommended by your Clinic. Begin involving your child in learning about this and what foods OK.

School Age: Involve your child in learning to help prepare formula and foods, and record keeping. Help your child learn about blood monitoring and doing levels as recommended by your Clinic.

Middle and High School:
Provide additional information about Maternal PKU.
Transition to self monitoring and diet management. (It's a process and will obviously need work and effort on part of parents and teen to make this transition;
Adult:
Checking with Specialist for recommendations about follow up and monitoring.
Learning about coverage for formula and special foods through insurance or other resources available in your state.

Family Information

- Child's Name:______________________________Nickname:_____________________________
  Date of Birth:________________________
  Diagnosis:____
  Blood Type:____

  Legal Guardian:____
  Address:____
  Phone_____________________________________

Family Members

- Mother's Name:____
  Address:____Email:__________________________
  Daytime Phone:_____________________________Evening Phone:_________________________

- Mother's Name:____
  Address:____Email:__________________________
  Daytime Phone:_____________________________Evening Phone:_________________________

- Sibling's Name:____________________Age:______ Name:____________________Age:______
- Sibling's Name:____________________Age:______ Name:____________________Age:______

- Other household members:____

- Important Family Information:____

- Language spoken at home:____
  Other language(s):____
  Interpreter needed? Yes: ☐ No: ☐
  Interpreter:____Phone:______________________

Emergency Contact

- Name:____
  Address:____
  Daytime Phone:_____________________________Evening Phone:_________________________

Supplies

- Medical Equipment Supplier (DME Supplier):______________________________

  Contact Person:____

  Phone:____________Fax:____________E-Mail:________________________

  Contact Person:____

  Phone:____________Fax:____________E-Mail:________________________

  Address:____

Notes (delivery schedule, order schedule, etc.):________________________________

ITEM	*DESCRIPTION*	*QUANTITY*	*NOTES*

Child's Name________________________________Date of Birth____________________

Health Care Providers

Tip:
Instead of filling out the form, staple your provider's business card onto the space provided.

Primary Care Provider

Name	Specialty (if any)
Clinic/Hospital Name	Telephone
Address	
Fax	Email

Medical Specialists and Health Care Providers

Name	Name
Specialty	Specialty
Address	Address
Telephone	Telephone
Fax	Fax
Email	Email
Clinic/Hospital Name	Clinic/Hospital Name
Frequency of Visits (how often)	Frequency of Visits (how often)

Name	Name
Specialty	Specialty
Address	Address
Telephone	Telephone
Fax	Fax
Email	Email
Clinic/Hospital Name	Clinic/Hospital Name
Frequency of Visits (how often)	Frequency of Visits (how often)

Child's Name_______________________________Date of Birth__________________

Health Care Providers

Name	Name
Specialty	Specialty
Address	Address
Telephone	Telephone
Fax	Fax
Email	Email
Clinic/Hospital Name	Clinic/Hospital Name
Frequency of Visits (how often)	Frequency of Visits (how often)

Name	Name
Specialty	Specialty
Address	Address
Telephone	Telephone
Fax	Fax
Email	Email
Clinic/Hospital Name	Clinic/Hospital Name
Frequency of Visits (how often)	Frequency of Visits (how often)

Name	Name
Specialty	Specialty
Address	Address
Telephone	Telephone
Fax	Fax
Email	Email
Clinic/Hospital Name	Clinic/Hospital Name
Frequency of Visits (how often)	Frequency of Visits (how often)

My Child's Profile

Child's Name:______________________________DOB:______________
Physician's Signature:____

IX. Immunization and Allergy Record Log

Immunization	Date	Date	Date	Date	Reaction if any	Physician
Diphtheria-Tetanus (DT)						
Diphtheria-Pertussis--Tetanus (DPT)						
Tetanus						
Polio (OPVIPV)						
Measles-Mumps-Rubella (MMR)						
Measles-Rubella (MR)						
Mumps						
Rubella (3-day Measles)						
Haemophilus Influenza (HIB)						
Hepatitis A						
Hepatitis B						
Varicella (Chicken Pox)						
Rotavirus						
Pneumovoccal (Pneumovac)						
Influenzae (Flu Shot)						

Skin Test Log:

Test	Date	Result	Provider
Newborn Screen			
Tuberculosis (TB)			

My Child's Profile

Child's Name:______________________________DOB:______________

Allergy Record Log:

Allergic reactions can be life threatening. Keep good record on all reactions.

Date	Allergy	Type of Reaction

Medications

Allergies:

Pharmacy: Phone:

MEDICATION	DATE STARTED	DATE STOPPED	DOSE / ROUTE (with or without food?)	TIME GIVEN	PRESCRIBED BY

Diet

Tracking Form

DATE	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
Tube Feeding							
Breakfast							
Lunch							
Dinner							
Snacks							
Notes							

CURRENT FORMULA RECIPE

Date______________

(amount)_____________grams/scoops/Tbsp. of____________________________(product)

(amount)___________________water

Other additives or instructions____

Foods/medical foods

___________________________mg/exchanges Phe

___________________________grams protein

Other instructions____

____

CURRENT FORMULA RECIPE

Date______________

(amount)_____________grams/scoops/Tbsp. of____________________________ (product)

(amount)___________________water

Other additives or instructions____

Foods/medical foods

___________________________mg/exchanges Phe

___________________________grams protein

Other instructions____

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Lab Work / Tests / Procedures

DATE	TEST	RESULT	COMMENTS

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Insurance/Funding Sources

- Insurance Name:___________________________
  Policy Number:___________________________
  Contact Person/Title:___________________________
  Address:___________________________
  Phone:__________ Fax:__________ Website/Email:__________

- Insurance Name:___________________________
  Policy Number:___________________________
  Contact Person/Title:___________________________
  Address:___________________________
  Phone:__________ Fax:__________ Website/Email:__________

- Insurance Name:___________________________
  Policy Number:___________________________
  Contact Person/Title:___________________________
  Address:___________________________
  Phone:__________ Fax:__________ Website/Email:__________

- Supplemental Security Income (SSI):___________________________
  Contact Person/Title:___________________________
  Address:___________________________
  Phone:__________ Fax:__________ Website/Email:__________

- Other:___________________________
  Contact Person/Title:___________________________
  Address:___________________________
  Phone:__________ Fax:__________ Website/Email:__________

- Other:___________________________
  Contact Person/Title:___________________________
  Address:___________________________
  Phone:__________ Fax:__________ Website/Email:__________

Medical Bill

Tracking Form

DATE	PROVIDER	COST	INSURANCE PAID	DATE PAID	FAMILY OWES	DATE PAID

Transitions - Looking Ahead

Your child and family will experience many transitions, small and large, over time. Three predictable transitions occur for most children: reaching school age, approaching adolescence, and moving from adolescence into adulthood. Many children do not experience these transitions in the way most children experience them. Other transitions may involve moving into new programs, working with new agencies and care providers, or making new friends. Transitions involve changes: adding new expectations, responsibilities, or resources, and letting go.

Looking at transitions may be hard, depending on your circumstances. You may have limited time just to do what needs to be done today. You may find it helpful, though, to jot down a few ideas about your child's and family's future. You might start by thinking about your child's and family's strengths. How can these strengths help you plan for "what's next" and for reaching long-term goals? What are your dreams and your fears about your child's and family's future?

Date:________________________________

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(Adapted from the Care Notebook with permission, Children's Hospital and Regional Medical Center, Seattle, WA, 2003.)
Family Voices of North Dakota 2005.