PROPIONIC ACIDEMIA FOUNDATION

This Care Notebook belongs to :

Place photo here

My Care Notebook

HOW TO USE THE CARE NOTEBOOK

The Care Notebook was created for you by parents who have a child with Propionic Acidemia. It can help you plan, coordinate care, and organize important health records.

This notebook has many forms to help you organize care. Use them to write down health care information, medical history, and other important facts. If you write everything down in one place, it will be easy to find when you need it. There is also information to gather, like contact information & labs results. Take your time and put the information together in an order that makes sense to you. You may want to use different forms and sections at different points in time.

Your Emergency Protocol Letter is one of your most important item of information that you have. Place a copy in your Care Notebook in the inside pocket of your binder.

Suggestions on where to keep additional copies of your emergency letter:

HOME: At the individual's home where it can be easily found, such as on the refrigerator

CAR: In the glove compartment of each parent/guardian's car.

PURSE/WALLET: In each parents' purse or wallet

SCHOOL: On file with the child's school, such as in the school nurse's office

DAY PROGRAM/DAY CARE: On file with the program, such as in the school nurse's office

CAMP: On file with the child's camp, such as in the nurse's office

EMERGENCY CONTACT PERSON: At the emergency contact's home listed on the form

LOCAL EMS: Give to local ambulance services and hospital emergency departments.

Ask for help. There are many people that can help you organize this notebook, such as a primary care provider, nurse, care coordinator, case manager, teacher, or family members. Feel free to call or e-mail PAF for help.

Make a section in your Care Notebook for each of the providers you use.
Suggested sections to start:

General information: About Me, Family Health History, Medications, Allergy Lists, Diagnoses, Birth History, Developmental History, Important Tests, Hospital Stays

Genetics: Nutrition Log, Clinic Visit Notes, Phone Log, Metabolic Tracking Form

Additional sections to consider:
Pediatrics/PCP, Cardiology, Nephrology, Ophthalmology, Audiology, Neurology, Hematology, Immunology, Therapists (Include Clinic Visit Notes and a Phone Log for each Provider)

You may want to put tabbed dividers for each section, so you can locate them easily.

Include copies of letters, insurance authorizations, receipts, prescriptions, and other documents in this notebook.

If you run out of space, purchase another 3-ring binder. The Glossary at the end of this book has the meaning of some words and terms you may hear at doctor's appointments or from other families.

Remember: This is YOUR Care Notebook; include information that is relevant to your situation. If there are sections that don't pertain to you, leave them out. If there are sections missing, add them. Everyone organizes information differently and this is one way you can organize.

Bring this notebook to appointments, meetings with health care providers, and emergency room visits.

If you need more forms, there are additional copies at the back of your notebook or you can download the most recent version available from the Propionic Acidemia Foundation at www.pafoundation.com.

PROPIONIC ACIDEMIA FOUNDATION
PAF

PO Box 151 Deerfield, IL 60015
Toll Free voice mail: 1-877-720-2192
E-mail: paf@pafoundation.com
Web-site: www.pafoundation.com

ALL ABOUT ME

My name is _____
First *Middle* *Last*

My nickname is _____

I live at ❒ Home ❒ School ❒ Foster home

❒ Hospital ❒ Other _____

The names of the people in my family are

First *Last* *Relationship to me*

_____

_____

_____

_____

_____

_____

_____

_____

_____

Other people who know me well are (friends, sitters, neighbors)

First *Last* *Relationship to me*

_____

_____

_____

_____

My Pets

My pet is a_____ Name of Pet_____

My other pet is a _____ Name of Pet_____

MORE ABOUT ME

My Favorites

Toys _____
Games_____
Hobbies _____
Songs _____
TV Shows _____
Other _____

Things I like to do during my free time _____
_____

Foods I like _____
_____

Foods I don't like _____
_____

I usually go to bed at_____ o'clock.
Before bed, I usually _____
_____

Things I need help with (for example: washing up, brushing teeth, dressing, etc.)
_____-_____
_____
_____

Things I can do myself_____
_____
_____

How I communicate (words, pictures, sign language, communication device)
_____

Date page completed: _____

FAMILY HEALTH HISTORY

Is there anyone in the family (parent, brother, sister, grandparents, aunt, uncle, cousin, etc.) with a similar disability or chronic illness? □ No □ Yes

If yes, who? _____

Does anyone in the family (parent, brother, sister, grandparents, aunt, uncle, cousin, etc.) have:

		If yes, relationship to child
1. Genetic conditions	□ Yes □ No	_____
2. Heart problems	□ Yes □ No	_____
3. Developmental disability	□ Yes □ No	_____
4. Seizure disorder	□ Yes □ No	_____
5. Diabetes	□ Yes □ No	_____
6. Blood disorder	□ Yes □ No	_____
7. Cancer	□ Yes □ No	_____
8. Vision impairment	□ Yes □ No	_____
9. Hearing impairment	□ Yes □ No	_____
10. Stroke	□ Yes □ No	_____
11. Other_____	□ Yes □ No	_____

_____

Has anyone in the family had genetic testing or counseling?

□ Yes □ No □ Don't Know

If yes, please describe_____

_____

_____

MEDICATIONS

Tip: Use a Post-it flag to mark the current medications on the list.

This form is used to keep track of all medications including vitamins, over-the-counter medicines, and dietary supplements. When medications or doses are changed, do not erase or black out the old information. Instead, draw a line through it and make a new entry to the list. This will give a complete record. You may also want to keep the pharmacy insert and prescription in this section.

Medication Name	Dosage/Route (How much/ how often? Mouth / g-tube)	Reason	Start Date	End Date	Prescribing Doctor	Notes

MEDICATIONS

Tip: Use a Post-it flag to mark the current medications on the list.

Medication Name	Dosage/Route (How much/ how often? Mouth / g-tube)	Reason	Start Date	End Date	Prescribing Doctor	Notes

Propionic Acidemia Foundation ...Searching for a cure, hope for our children.

DIAGNOSES

Diagnosis Given Provider who Gave Diagnosis Date Noted Notes

ALLERGIES

Food, Drug, Other	Date of Reaction	Reaction	Treatment	Outcome

BIRTH AND DEVELOPMENT:
ABOUT MOTHER'S PREGNANCY

Please describe any illnesses or problems during pregnancy.

_____

_____

Method of delivery □ Vaginal □ Caesarian □ Breech □ VBAC

Were there complications at delivery? □ No □ Yes (please describe_____

_____

Mother's Obstetrician / Nurse Midwife_____ Phone_____

Mother's Primary Care Provider_____ Phone_____

Delivery Setting

Name of Hospital/Birth Center_____Phone_____

Address_____

Was child transferred to another hospital □ No □ Yes

If yes, name of hospital_____Phone_____

Address_____

BIRTH AND DEVELOPMENT

Birthweight ___ lbs ____oz Length ___inches

Was baby full-term (37 or more weeks)? □ Yes □ No If no, weeks of gestation

Apgar scores at 1 minute_____ at 5 minutes _____

Age at first discharge from hospital _____

Baby was fed □ breast milk □ formula -If fed formula, list brand _____

Developmental Milestones

Milestone	Age when	Notes
Smiled		
Held up head		
Rolled over		
Sat up		
Got first tooth		
Started solid food		
Crawled		
Spoke first word		
Waved "bye bye"		
Walked		
Spoke first aentence		
Toilet trained		

Tip: Ask your primary care provider (PCP) for information you don't know (such as Apgar scores and growth measurements).

CONTACT INFORMATION

Personal, Parent, and Emergency Contact Information

Personal Information

Name _____

Date of Birth_____

Primary Language_____

Phone_____

E-mail_____

Parent/Guardian/Trusted Adult 1

Name _____

Relationship_____

Phone_____

E-mail_____

Parent/Guardian/Trusted Adult 2

Name _____

Relationship_____

Phone_____

E-mail_____

Emergency Contact 1

Name _____

Relationship_____

Phone_____

Emergency Contact 2

Name _____

Relationship_____

Phone_____

SCHOOL / DAY CARE CENTER / CAMP / DAY PROGRAM

Name _____

Address_____Phone_____

Principal/Director_____ Phone_____

Email_____

Nurse _____ Phone_____Email_____

Teacher(s) _____Phone_____Email_____

Aide(s)_____

Special Education Contacts_____ Phone_____ Email_____

_____ Phone_____ Email_____

Therapist(s)_____ Phone_____ Email_____

_____ Phone_____ Email_____

_____ Phone_____ Email_____

Psychologist _____ Phone_____ Email_____

Guidance Counselor_____ Phone_____ Email_____

Parent Advisory Committee (PAC) Contact_____ Phone_____

Is there a school-based health center at the school? ☐ Yes ☐ No

If yes, Name of Center Phone_____

Transportation (i.e., bus service, taxi, etc...)

Agency Name:_____ Driver Name:_____

Contact Name_____Phone_____

Local Hospital

Name_____
Address_____
_____
Phone_____
Fax_____
E-mail_____
Contact_____

Advanced Hospital

Name_____
Address_____
_____
Phone_____
Fax_____
E-mail_____
Contact_____

Pharmacy

Name_____
Address_____
_____
Phone_____
Fax_____
E-mail_____
Contact_____

Specialty Pharmacy

Name_____
Address_____
_____
Phone_____
Fax_____
E-mail_____
Contact_____
_

DME Provider

Name_____
Address_____
_____
Phone_____
Fax_____
E-mail_____
Contact_____

DME Provider

Name_____
Address_____
_____
Phone_____
Fax_____
E-mail_____
Contact_____

Tip: Instead of filling out the form, staple your provider's business card onto the space provided or insert business card holder. (Avery #76009)

Geneticist

Name_____
Address_____
Phone_____
Fax_____
E-mail_____
Clinic/Hospital_____
Frequency of visits_____

Dietician

Name_____
Address_____
Phone_____
Fax_____
E-mail_____
Clinic/Hospital_____
Frequency of visits_____

Genetic Counselor

Name_____
Address_____
Phone_____
Fax_____
E-mail_____
Clinic/Hospital_____
Frequency of visits_____

Social Worker

Name_____
Address_____
Phone_____
Fax_____
E-mail_____
Clinic/Hospital_____
Frequency of visits_____

Primary Care Physician/Pediatrician

Name_____
Address_____
Phone_____
Fax_____
E-mail_____
Clinic/Hospital_____
Frequency of visits_____

Case Manager

Name_____
Address_____
Phone_____
Fax_____
E-mail_____
Clinic/Hospital_____
Frequency of visits_____

Medical Specialist

Name____________________________
Specialty__________________________
Address__________________________
Phone___________________________
Fax_____________________________
E-mail__________________________
Clinic/Hospital____________________
Frequency of visits________________

Medical Specialist

Name____________________________
Specialty__________________________
Address__________________________
Phone___________________________
Fax_____________________________
E-mail__________________________
Clinic/Hospital____________________
Frequency of visits________________

Medical Specialist

Name____________________________
Specialty__________________________
Address__________________________
Phone___________________________
Fax_____________________________
E-mail__________________________
Clinic/Hospital____________________
Frequency of visits________________

Medical Specialist

Name____________________________
Specialty__________________________
Address__________________________
Phone___________________________
Fax_____________________________
E-mail__________________________
Clinic/Hospital____________________
Frequency of visits________________

Medical Specialist

Name____________________________
Specialty__________________________
Address__________________________
Phone___________________________
Fax_____________________________
E-mail__________________________
Clinic/Hospital____________________
Frequency of visits________________

Medical Specialist

Name____________________________
Specialty__________________________
Address__________________________
Phone___________________________
Fax_____________________________
E-mail__________________________
Clinic/Hospital____________________
Frequency of visits________________

Therapist

Name______________________________
Specialty___________________________
Address____________________________
Phone______________________________
Fax________________________________
E-mail_____________________________
Clinic/Hospital______________________
Frequency of visits__________________

Therapist

Name______________________________
Specialty___________________________
Address____________________________
Phone______________________________
Fax________________________________
E-mail_____________________________
Clinic/Hospital______________________
Frequency of visits__________________

Therapist

Name______________________________
Specialty___________________________
Address____________________________
Phone______________________________
Fax________________________________
E-mail_____________________________
Clinic/Hospital______________________
Frequency of visits__________________

Therapist

Name______________________________
Specialty___________________________
Address____________________________
Phone______________________________
Fax________________________________
E-mail_____________________________
Clinic/Hospital______________________
Frequency of visits__________________

Therapist

Name______________________________
Specialty___________________________
Address____________________________
Phone______________________________
Fax________________________________
E-mail_____________________________
Clinic/Hospital______________________
Frequency of visits__________________

Therapist

Name______________________________
Specialty___________________________
Address____________________________
Phone______________________________
Fax________________________________
E-mail_____________________________
Clinic/Hospital______________________
Frequency of visits__________________

Home Health Agency

Name _____

Address_____

Contact_____Phone _____

E-mail_____Fax_____

Nurse/therapist _____Phone_____

Nurse/therapist _____Phone_____

Nurse/therapist _____Phone_____

Nurse/therapist _____Phone_____

HEALTH INSURANCE

Tip: Include a photocopy of the front and back of your insurance cards in a page protector for easy removal. Include dental insurance information and vision if applicable.

Primary Insurance Provider

Plan Name_____

Subscriber Name _____

Relationship_____

Subscriber's Date of Birth_____

Subscriber ID#_____Group #_____

Address_____

Case Manager_____

Phone_____

Secondary Insurance Provider

Plan Name_____

Subscriber Name _____

Relationship_____

Subscriber's Date of Birth_____

Subscriber ID#_____Group #_____

Address_____

Case Manager_____

Phone_____

MEDICAL BILL TRACKING FORM

Tip: Begin a new page for each calendar year to help with income taxes.

Date of Service	Provider	Amount Billed ($)	Insurance Paid	Date Paid	Family Owes (+ co-pay)	My Payment/ Date paid

MEDICAL SUPPLIES/EQUIPMENT

Tip: Insert authorization forms for equipment and supplies behind this section.

Description of Item and Item #	
Provider/Vendor Name	
Contact Person	Phone
Prescribed by	Phone
Reason Prescribed	
Contact Person for Service/Insurance	Phone
Approval Comments (for example: kinds of service needed, part numbers, costs)	

Description of Item and Item #	
Provider/Vendor Name	
Contact Person	Phone
Prescribed by	Phone
Reason Prescribed	
Contact Person for Service/Insurance	Phone
Approval Comments (for example: kinds of service needed, part numbers, costs)	

Description of Item and Item #	
Provider/Vendor Name	Phone
Contact Person	Phone
Prescribed by	
Reason Prescribed	
Contact Person for Service/Insurance	Phone
Approval Comments (for example: kinds of service needed, part numbers, costs)	

SUPPLY TRACKING FORM

Item #	Description	Amount on hand	Date Ordered	Quantity Ordered	Date Received	Quantity Received

IMPORTANT TESTS

Tip: Insert lab & test reports behind this section.

Blood/ X-ray/ CT /MRI Other_____	Date Performed
Description	
Doctor who Ordered	Phone
Test Results	
Location of Test	Phone
Record Comments	

Blood/ X-ray/ CT /MRI Other_____	Date Performed
Description	
Doctor who Ordered	Phone
Test Results	
Location of Test	Phone
Record Comments	

HOSPITAL STAYS

Tip: Insert discharge summaries behind this section.

Date of Admission	Date of Discharge
Name of Hospital	Phone
Address	
Doctor(s)/Surgeon(s)	
Reason for Admission	
Outcome	

Date of Admission	Date of Discharge
Name of Hospital	Phone
Address	
Doctor(s)/Surgeon(s)	
Reason for Admission	
Outcome	

Date of Admission	Date of Discharge
Name of Hospital	Phone
Address	
Doctor(s)/Surgeon(s)	
Reason for Admission	
Outcome	

DIAGNOSIS OF PROPIONIC ACIDEMIA

Diagnosis Given_____

Were you/your child Newborn Screened? □ Yes □ No If yes, did the screening detect an abnormality? □ Yes □ No

Did you/your child have a metabolic crisis prior to diagnosis? □ Yes □ No

If yes, was the ammonia elevated? □ Yes □ No If yes, what was the highest level? ___
Was dialysis used? □ Yes □ No
Were ammonia lowering medications used? □ Yes □ No

Gene Mutation 1: _____ Gene Mutation 2:_____
(include copy of mutation analysis in this section)

Describe other details of the diagnosis and relevant crisis:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Home Health Agency

Name _____

Address_____

Contact_____Phone _____

E-mail_____Fax_____

Nurse/therapist _____Phone_____

Nurse/therapist _____Phone_____

Nurse/therapist _____Phone_____

Nurse/therapist _____Phone_____

MONTHLY PLANNER

MONTH

MON	TUE	WED	THU	FRI	SAT	SUN

TOP PRIORITIES

1
2
3
4
5
6

NOTES

NUTRITION LOG

Name:_____
Date:_____

	MEAL	FORMULA	PROTEIN	CALORIES	FLUIDS
BREAKFAST	DAILY GOAL				
SNACK					
LUNCH					
SNACK					
DINNER					
OVERNIGHT					
	TOTAL				

FORMULA RECIPE

_____ _____ _____

_____ _____ _____

_____ _____ _____

_____ _____ _____

_____ _____ _____

_____ _____ _____

Tip: Photocopy this page so that you will have a sheet for every day. You may only need a Nutrition log for three days prior to your clinic visit with genetics and your nutritionist

IMPORTANT TESTS

Tip: Insert lab and test reports behind this section.

Blood/ X-ray/ CT /MRI Other_____	Date Performed
Description	
Doctor who Ordered	Phone
Test Results	
Location of Test	Phone
Record Comments	
Blood/ X-ray/ CT /MRI Other_____	Date Performed
Description	
Doctor who Ordered	Phone
Test Results	
Location of Test	Phone
Record Comments	

PHONE LOG

Provider _____

It is easy to lose track of what you discussed with providers when you have so many different phone calls. Use this form to keep track of phone calls and other conversations you have with health care providers. Put a page in your Care Notebook for each provider.

Date / Time of Call	Name of Person on Call	Phone	Notes (what was discussed or decided)

LABS

Tip: Insert lab results behind this sheet.

DATE	TEST	RESULT	COMMENTS

SURGERIES AND PROCEDURES

Tip: Insert surgical report behind this page.

DATE	Type of Procedure/Surgery	Physician/Hospital

GLOSSARY OF COMMONLY USED TERMS

Amino Acids: When proteins are digested in the diet, amino acids remain - amino acids are either essential (obtained through diet) or non-essential (made by the body from the essential amino acids).*

Ammonia: A by-product of protein metabolism.*

Anion Gap: The difference between the sum of cations and anions found in plasma or serum. The anion gap is used to aid in the differential diagnosis of metabolic acidosis. It is calculated by subtracting the chloride and bicarbonate levels from the sodium plus potassium levels.

Asymptomatic: Showing no symptoms.*

Autosomal Recessive Inherited Disorder: A characteristic or disorder occurring when an individual receives two copies of a mutated gene for that condition, one from the mother and one from the father

Biochemical Pathway: Systems in the body for processing molecules for useful purposes.*

Biotin: A vitamin Cofactor for carboxylase enzymes. Essential for metabolism of proteins, carbohydrates and fats.

Branched Chain Amino Acid (BCAA): L-Leucine, L-Isoleucine, L-Valine are essential amino acids because humans cannot survive unless they are present in the diet. They are easily converted to ATP, critical to energy and muscle metabolism. They aid in hemoglobin formation, which helps to stabilize blood sugar and lower elevated blood sugar levels. L-Leucine decreases blood sugar and boosts tissue healing, including bone. L-isoleucine is essential for hemoglobin formation and regulates blood sugar and energy levels. L-Valine acts as a natural stimulant and is involved in tissue regeneration and nitrogen balance. *

Cardiomyopathy: Cardiomyopathy is a group of chronic disorders affecting the muscle of the heart resulting in impairment of the pumping function of the heart.

Carnitine: This essential fatty acid metabolism cofactor helps to move the fatty acid to the mitochondria from the cytoplasm of the cell.

Carrier: Individuals carrying an abnormal gene that can be transmitted to their offspring. These individuals do not show evidence of the disorder.*

Catabolism: The breakdown of lean muscle mass to obtain amino acids (for growth and development) and energy, resulting from inadequate supply in the diet. Results in excess production of ammonia.* Any metabolic process by which organisms convert substances into excreted compounds.

Chronic: A situation or disease with a long duration.*

Cofactor: A Cofactor is any substance that needs to be present in addition to an enzyme to catalyze a certain reaction.

Constipation: Difficult, incomplete, or infrequent evacuation of dry hardened feces from the bowels. Can cause PA's serious illness.**

Cyclic: Recurring or moving in cycles. **

Deficiency: A lower amount than necessary for functioning. *

Dehydration: Excessive loss of water from the body or from an organ or body part, as from illness or fluid deprivation. **

Developmental Disabilities: A chronic mental or physical impairment that results in decreased ability of an individual to reach appropriate age-level developmental goals.*

DNA: Deoxyribonucleic acid (DNA) is the chemical inside the nucleus of all cells that carries the genetic instructions for making living organisms.*

Electrolytes: Any of various ions, such as sodium or chloride, required by cells to regulate the electric charge and flow of water molecules across the cell membrane. The primary ions of electrolytes are sodium, potassium, calcium, magnesium, chloride, phosphate and bicarbonate.**

Emesis: The action or process of vomiting.

Enzyme: A protein molecule that helps other organic molecules enter into chemical reactions with one another but is itself unaffected by these reactions.**

Enzymatic Assay: laboratory methods for measuring enzymatic activity.**

Etiology: The origins of a disease.*

Fibroblasts: A cell that is present in connective tissue and active in making and secreting collagen.* Skin cells.

Gene: A segment of DNA that has a particular purpose, i.e., that codes for (contains the chemical information necessary for the creation of) a specific enzyme or other protein.**

Hyperammonemia: Abnormally high levels of ammonia in the blood; if untreated, causing severe agitation, vomiting, lethargy, coma and death.*

Hypothermia: Abnormally low body temperature below 95 degrees F, causing heart and respiration slowing and paleness.*

Hypotonia (low tone): A condition in which there is diminution or loss of muscular tonicity, resulting in stretching of the muscles beyond their normal limits.**

Isoleucine: An essential amino acid found in proteins. One of the restricted amino acids for PA patients.

Ketone or Ketone Bodies: A ketone is an intermediate product of the breakdown of fats in the body; any of three compounds (acetoacetic acid, acetone, and/or beta-hydroxybutyric acid) found in excess in blood and urine of persons with metabolic disorders** Ketones are used as a measure of metabolic instability in PA patients.

Ketosis: A pathological increase in the production of ketone bodies. Ketosis is a stage in metabolism occurring when the liver has been depleted of stored glycogen and switches to a fasting mode such as occurs during sleep, during dieting, and during the body's response to starvation.** In PA, a measure of metabolic instability.

Late-onset disorder: Characterized by mild, moderate or severe symptoms (occurring anytime after the neonatal period) in early or late childhood resulting from mutations allowing varying degrees of partial enzyme activity. Also sometimes referred to as “partial” defects.* A late-onset metabolic crisis can be as severe and life-threatening as the neonatal form.

Lethargy: Sleepiness. *

Liver: A large vascular organ in the body that causes important changes in substances in the body in order for the body to use these substances.*

Metabolic Acidosis: Decreased pH and bicarbonate concentration of the body fluids caused either by the accumulation of excess acids stronger than carbonic acid or by abnormal losses of bicarbonate from the body.** A metabolic derangement of acid-base balance where the blood pH is abnormally low.

Metabolic Pathway: A cascade of chemical reactions by which the chemical changes in living cells provide energy for vital processes in the body. Energy production in the cell occurs in the mitochondria.

Metabolite: A substance produced by metabolic action or necessary for metabolic process. In PA, certain metabolites can reach toxic levels.* Any substance produced by metabolism or by a metabolic process.

Methionine: Amino acid found in most proteins and essential for nutrition. Restricted amino acid for patients with Propionic Acidemia.**

Mutation: A change in genetic material occurring spontaneously or by induction, which changes the original expression (function or purpose) of the gene.*

Neonatal Onset Disorder: Severe, catastrophic disorder with life-threatening symptoms occurring in the neonatal period resulting from null/zero enzyme mutations or severely impaired enzyme activity.*

Neutropenia: An abnormal decrease in the number of neutrophils in the blood. **

Odd Chain Fatty Acid: Fatty acids with an odd number of carbon atoms.

Organic Acidemia: Inherited disorders of amino acid catabolism in which toxic substances are produced as a result of an enzymatic blockage

Pancreatitis: Inflammation of the pancreas.

Partial Activity: Not completely active, may be missing vital components. *

Plasma: Liquid part of the blood in which blood cells are suspended. *

Proband: An individual with a particular disorder who causes a study of his hereditary and genetic factors to determine if other members of the family have the same disease or carry it.* The proband might for example be a baby with propionic acidemia.

Prenatal: Before birth. *

Protein: Essential to all living cells, simplified by body processes to simple alpha-amino acids. * Twenty different amino acids are commonly found in proteins and each protein has a unique, genetically defined amino acid sequence which determines its specific shape and function.

Quantitative Amino Acids: Blood test done to measure levels of all amino acids individually.

Rapid Onset: Beginning quickly without warning.*

Seizures: A temporary change in brain performance due to abnormal electrical activity of a specific group of cells in the brain that either present with sudden muscle contractions, decreased level of consciousness, and several other symptoms.

Serum or Plasma Ammonia level: Amount of ammonia concentration present in blood or plasma, used to monitor ammonia levels in PA's. *

Supplementation: A substance added to the diet to counteract a deficiency or potential deficiency. *

Threonine: Amino acid found in most proteins and essential for nutrition. Restricted amino acid for patients with Propionic Acidemia. **

Transport: To carry from one area to another in the body or within a cell. *

Tremor Ataxia: Trembling or shaking and lack of control of voluntary muscles. *

Triggering Event: An episode that causes a reaction or illness. *

Urea: A product of protein breakdown of amino acids, excreted in the urine. *

Valine: Amino acid found in most proteins and essential for nutrition. Restricted amino acid for patients with Propionic Acidemia. **

Waste: Unusable or excess material, lost by breaking down of the body's tissues. * Toxic by-products of cellular processes that are excreted from the body.

References:

* National Urea Cycle Foundation
** The American Heritage® Dictionary of the English Language, Fourth Edition. Houghton Mifflin Company, 2004.
** The American Heritage Stedman's Medical Dictionary. Houghton Mifflin Company, 2002.
** WordNet 1.7.1. Princeton University, 2001

CLINIC VISIT

Appointment Date: _____Appointment Time:_____

Labs Ordered: _____

Tests Ordered: _____

Questions: _____

_____

_____

Notes:

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

PHONE LOG

Provider _____

It is easy to lose track of what you discussed with providers when you have so many different phone calls. Use this form to keep track of phone calls and other conversations you have with health care providers. Put a page in your Care Notebook for each provider.

Date & Time of Call	Name of Person on Call	Phone	Notes (what was discussed or decided)

LABS

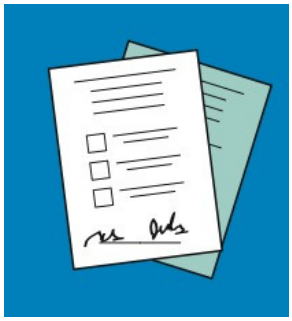
Tip: Insert lab results behind this sheet.

DATE	TEST	RESULT	COMMENTS

MEDICAL BILL TRACKING FORM

Tip: Begin a new page for each calendar year to help with income taxes.

Date of Service	Provider	Amount Billed ($)	Insurance Paid	Date Paid	Family Owes (+ co-pay)	My Payment/ Date paid



Additional Forms

MEDICATIONS

Tip: Use a Post-it flag to mark the current medications on the list.

Medication Name	Dosage/Route How much/ how often? Mouth/g-tube)	Reason	Start Date	End Date	Prescribing Doctor	Notes

DIAGNOSES

Diagnosis Given Provider who Gave Diagnosis Date Noted Notes

ALLERGIES

Food, Drug, Other	Date of Reaction	Reaction	Treatment	Outcome

Tip: Insert surgical report behind this page.

SURGERIES AND PROCEDURES

DATE	Type of Procedure/Surgery	Physician/Hospital

CONTACT INFORMATION

Personal, Parent, and Emergency Contact Information

Personal Information

Name _____

Date of Birth_____

Primary Language_____

Phone_____

E-mail_____

Parent/Guardian/Trusted Adult 1

Name _____

Relationship_____

Phone_____

E-mail_____

Parent/Guardian/Trusted Adult 2

Name _____

Relationship_____

Phone_____

E-mail_____

Emergency Contact 1

Name _____

Relationship_____

Phone_____

Emergency Contact 2

Name _____

Relationship_____

Phone_____

HOSPITAL STAYS

Tip: Insert discharge summaries behind this section.

Date of Admission	Date of Discharge
Name of Hospital	Phone
Address	
Doctor(s)/Surgeon(s)	
Reason for Admission	
Outcome	

Date of Admission	Date of Discharge
Name of Hospital	Phone
Address	
Doctor(s)/Surgeon(s)	
Reason for Admission	
Outcome	

Date of Admission	Date of Discharge
Name of Hospital	Phone
Address	
Doctor(s)/Surgeon(s)	
Reason for Admission	
Outcome	

FAMILY HEALTH HISTORY

Is there anyone in the family (parent, brother, sister, grandparents, aunt, uncle, cousin, etc.) with a similar disability or chronic illness? □ No □ Yes

If yes, who? _____

Does anyone in the family (parent, brother, sister, grandparents, aunt, uncle, cousin, etc.) have:

		If yes, relationship to child
1. Genetic conditions	□ Yes □ No	_____
2. Heart problems	□ Yes □ No	_____
3. Developmental disability	□ Yes □ No	_____
4. Seizure disorder	□ Yes □ No	_____
5. Diabetes	□ Yes □ No	_____
6. Blood disorder	□ Yes □ No	_____
7. Cancer	□ Yes □ No	_____
8. Vision impairment	□ Yes □ No	_____
9. Hearing impairment	□ Yes □ No	_____
10. Stroke	□ Yes □ No	_____
11. Other_____	□ Yes □ No	_____

_____

Has anyone in the family had genetic testing or counseling?

□ Yes □ No □ Don't Know

If yes, please describe_____

_____

_____

Medical Specialist

Name________________________________
Specialty____________________________
Address_____________________________
Phone______________________________
Fax_________________________________
E-mail______________________________
Clinic/Hospital______________________
Frequency of visits__________________

Medical Specialist

Name________________________________
Specialty____________________________
Address_____________________________
Phone______________________________
Fax_________________________________
E-mail______________________________
Clinic/Hospital______________________
Frequency of visits__________________

Medical Specialist

Name________________________________
Specialty____________________________
Address_____________________________
Phone______________________________
Fax_________________________________
E-mail______________________________
Clinic/Hospital______________________
Frequency of visits__________________

Medical Specialist

Name________________________________
Specialty____________________________
Address_____________________________
Phone______________________________
Fax_________________________________
E-mail______________________________
Clinic/Hospital______________________
Frequency of visits__________________

Medical Specialist

Name________________________________
Specialty____________________________
Address_____________________________
Phone______________________________
Fax_________________________________
E-mail______________________________
Clinic/Hospital______________________
Frequency of visits__________________

Medical Specialist

Name________________________________
Specialty____________________________
Address_____________________________
Phone______________________________
Fax_________________________________
E-mail______________________________
Clinic/Hospital______________________
Frequency of visits__________________

MEDICAL SUPPLIES/EQUIPMENT

Tip: Insert authorization forms for equipment and supplies behind this section.

Description of Item and Item #	
Provider/Vendor Name	
Contact Person	Phone
Prescribed by	Phone
Reason Prescribed	
Contact Person for Service/Insurance Approval	Phone
Comments (for example: kinds of service needed, part numbers, costs)	

Description of Item and Item #	
Provider/Vendor Name	
Contact Person	Phone
Prescribed by	Phone
Reason Prescribed	
Contact Person for Service/Insurance Approval	Phone
Comments (for example: kinds of service needed, part numbers, costs)	

Description of Item and Item #	
Provider/Vendor Name	
Contact Person	Phone
Prescribed by	Phone
Reason Prescribed	
Contact Person for Service/Insurance Approval	Phone
Comments (for example: kinds of service needed, part numbers, costs)	

SUPPLY TRACKING FORM

Item #	Description	Amount on hand	Date Ordered	Quantity Ordered	Date Received	Quantity Received

SCHOOL / DAY CARE CENTER / CAMP / DAY PROGRAM

Name _____

Address_____Phone_____

Principal/Director_____ Phone_____

Email_____

Nurse _____ Phone_____Email_____

Teacher(s) _____Phone_____Email_____

Aide(s)_____

Special Education Contacts_____ Phone_____ Email_____

_____ Phone_____ Email_____

Therapist(s)_____ Phone_____ Email_____

_____ Phone_____ Email_____

_____ Phone_____ Email_____

Psychologist _____ Phone_____ Email_____

Guidance Counselor_____ Phone_____ Email_____

Parent Advisory Committee (PAC) Contact_____ Phone_____

Is there a school-based health center at the school? ☐ Yes ☐ No

If yes, Name of Center Phone_____

Transportation (i.e., bus service, taxi, etc...)

Agency Name:_____ Driver Name:_____

Contact Name_____Phone_____

IMPORTANT INFORMATION FOR A SITTER

Parent(s)/Guardian(s) Name(s)_____

I/we will be at_____ I/we will be home around_____

Phone number(s)_____

Special Instructions_____

_____

Significant events from past 48 hours_____

_____

Feeding/medication instructions/times_____

_____

_____

In Case of an Emergency: CALL 911

Name _____Date of Birth _____

Home Phone _____

Address _____

Doctor's Name_____ Phone _____

Other person to call in case of an emergency (i.e. relative, neighbor, friend)

_____

Allergies _____

Extra equipment/supplies are located _____

Fuse box / breaker location _____Fire extinguisher location_____

Flashlight location _____ Emergency bag location_____

EVENT DIARY

Use this sheet to keep track of important health related events. Some examples include seizures, injury, or anything that would be unusual.

DATE	ACTIVITY/INFORMATION

MEETING/APPOINTMENT LOG

Use this form to keep track of meetings and appointments. Under notes include what was discussed, decided, and next steps.

DATE/TIME OF MEETING	NAME OF PERSON/ AGENCY	CONTACT INFORMATION	NOTES

HEALTH INSURANCE

Tip: Include a photocopy of the front and back of your insurance cards in a page protector for easy removal. Include dental insurance information and vision if applicable.

Primary Insurance Provider

Plan Name_____

Subscriber Name _____

Relationship_____

Subscriber's Date of Birth_____

Subscriber ID#_____Group #_____

Address_____

Case Manager_____

Phone_____

Secondary Insurance Provider

Plan Name_____

Subscriber Name _____

Relationship_____

Subscriber's Date of Birth_____

Subscriber ID#_____Group #_____

Address_____

Case Manager_____

Phone_____

METABOLIC TRACKING FORM

MONTH:_____ YEAR:_____

DAY	VOMITING	KETONES	FORMULA	BM	NOTES
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					
11					
12					
13					
14					
15					
16					
17					
18					
19					
20					
21					
22					
23					
24					
25					
26					
27					
28					
29					
30					
31					

MONTHLY PLANNER

MONTH

MON	TUE	WED	THU	FRI	SAT	SUN

TOP PRIORITIES

1
2
3
4
5
6

NOTES

Nutrition Log

Name:_____
Date:_____

	MEAL	FORMULA	PROTEIN	CALORIES	FLUIDS
BREAKFAST	DAILY GOAL				
SNACK					
LUNCH					
SNACK					
DINNER					
OVERNIGHT					
	TOTAL				

FORMULA RECIPE

Tip: Photocopy this page so that you will have a sheet for every day. You may only need a Nutrition log for three days prior to your clinic visit with genetics and your nutritionist