This Care Notebook Belongs To:

Place Photo Here

Propionic Acidemia Foundation
1963 McCraren Road
Highland Park, IL 60035

Toll Free voice mail: 1-877-720-2192
Direct Contact: 1-847-452-7528
Fax: 1-877-720-2192

E-mail: paf@pafoundation.com
Web-site: www.pafoundation.com

How to Use the PAF Care Notebook

The Care Notebook was created for you, a parent of a child with Propionic Acidemia by other parents that have children with PA. It can help you plan and coordinate care for your child. In the Care Notebook you will find*:*

- Ways to organize your child's health information
- Information about caring for your child's special needs
- Resources
- Tips from other parents of children with special health care needs

The Care Notebook has many forms to fill out and a lot of information to read through. Take your time to fill out the forms that are useful to you, gather your child's records, and read through the chapters. You may want to use different forms and sections at different points in your child's life. This notebook can be very helpful to you and your child's health care providers.

Organizing Tips:

- Put your child's ***Emergency Protocol Letter*** (from his/her doctor) in the front of your book. Take it with you every time you go to a health care visit, whether it is a check-up or an emergency visit.

- Use the calendar to write down important dates and appointments.

- Write down information about your child's health and health care.

- Include copies of letters, bills, receipts, prescriptions, and other documents in this notebook. If you run out of space, it is time to buy 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.

- Check the ***PAF Website at www.pafoundation.com*** **.** It has the names, addresses, phone numbers, and web addresses for many useful organizations and programs. Go to "Sites of Interest" and click on "State by State". You will find useful information on resources within your state.

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

- Remember: this is your Care Notebook. If there are sections that don't pertain to your child, leave them out. If there are sections missing, add them. Everyone organizes papers differently and this is one way you can organize.

Bring this notebook to your child's appointments and meetings with health care providers.

Complete Care Notebook

Table of Contents

Important Information about Your Child

This chapter has many forms to help you organize and plan your child's care. Use them to write down your child's 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.

Information Forms Checklist

- ❑ Parent/Guardian and Emergency Contact Information
- ❑ Emergency Information Form for Children with Special Needs
- ❑ Protocol
- ❑ Health Insurance Plan
- ❑ Hospitals
- ❑ Health Care Providers
- ❑ Other Health Care Providers
- ❑ Formula Recipe
- ❑ Medications
- ❑ Pharmacies
- ❑ Supplies/Equipment
- ❑ Home Health Agency
- ❑ School/Day Care Center
- ❑ All about Me
- ❑ Birth and Development: About Mother's Pregnancy
- ❑ Birth and Development: About Your Baby
- ❑ Family Health History
- ❑ Diagnoses
- ❑ Allergies
- ❑ Important Tests
- ❑ Hospital Stays
- ❑ Medical Bill Tracking Form

Master Forms
- ❑ Event Diary
- ❑ Meeting/Appointment Log
- ❑ Phone Log
- ❑ Important Information for a Sitter

> If you need more forms, they are downloadable from the Propionic Acidemia Foundation at www.pafoundation.com.

Parent/Guardian and Emergency Contact Information

Child

Name Nickname

Address

Social Security # Date of Birth

First Language Other Languages Spoken

Parent(s)/Guardian(s)

Name Relationship to Child

Address

Telephone: Home Work Cell

First Language Other Languages Spoken

Additional Parent(s)/Guardian(s)

Name Relationship to Child

Address

Telephone: Home Work Cell

First Language Other Languages Spoken

Does your child have more than one residence? Yes ☐ No

If yes, please explain _____

Emergency Contact

Name Relationship to Child

Address

Telephone: Home Work Cell

Emergency Information Form for Children with Special Needs (http://www.aap.org/advocacy/blankform.pdf)

The following form gives emergency providers the information they need to properly care for your child. Ask your child's primary care provider (PCP) to fill out and sign this form. Give a copy of this form to anyone who may take care of your child in an emergency.

It is very important to **update** the form after any of the following events:

- Important changes in your child's condition or diagnosis
- Any major surgical procedures
- Major changes in medications or dosages
- Changes in health care providers

After updating the form, remember to give new copies to emergency medical services (EMS), your child's providers, and caregivers.

Suggestions on where to keep copies of this form:

- **Health Care Provider's Office**: On file with each of the child's health care providers, including specialists.
- **Home:** At the child's home in a place where it can be easily found, such as on the refrigerator.
- **Car:** In the glove compartment of each parent/guardian's car.
- **Work:** At each parent's workplace.
- **Purse/Wallet:** In each parent's purse or wallet.
- **School:** On file with the child's school, such as in the school nurse's office.
- **Child's Belongings:** With the child's belongings when traveling.
- **Emergency Contact Person:** At the home of the emergency contact person listed on the form.
- **Local EMS:** Give to local ambulance services and hospital emergency departments. Keep more copies on-hand to give to emergency service providers during an emergency situation.

Emergency Information Form for Children With Special Needs

Last name:

American College of Emergency Physicians®

American Academy of Pediatrics

Date form completed	Revised	Initials
By Whom	Revised	Initials

Name:	Birth date:	Nickname:
Home Address:	Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:	
Signature/Consent*:		
Primary Language:	Phone Number(s):	

Physicians:

Primary care physician:	Emergency Phone:
	Fax:
Current Specialty physician:	Emergency Phone:
Specialty:	Fax:
Current Specialty physician:	Emergency Phone:
Specialty:	Fax:
Anticipated Primary ED:	Pharmacy:
Anticipated Tertiary Care Center:	

Diagnoses/Past Procedures/Physical Exam:

1.

2.

3.

4.

Synopsis:

Baseline physical findings:

Baseline vital signs:

Baseline neurological status:

*Consent for release of this form to health care providers

Last name:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1.	
2.	
3.	
Procedures to be avoided	**and why:**
1.	
2.	
3.	

Immunizations (mm/yy)

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: Print Name:

© American College of Emergency Physicians and American Academy of Pediatrics. Permission to reprint granted with acknowledgement.

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

Name of Plan

Telephone

Address

Subscriber (Name of Policy Holder)

Subscriber ID#

Group #

Case Manager/Care Coordinator Telephone

Other Contacts Telephone

Secondary Insurance

Name of Plan

Telephone

Address

Subscriber (Name of Policy Holder)

Subscriber ID#

Group #

Case Manager/Care Coordinator Telephone

Other Contacts Telephone

Hospitals

Main Hospital

Name of Hospital

Address

Medical Record #

Hospital Operator Telephone

Emergency Department Telephone

Contact Person Name Title

Telephone Fax E-mail

Other Hospital

Name of Hospital

Address

Medical Record #

Hospital Operator Telephone

Emergency Department Telephone

Contact Person Name Title

Telephone Fax E-mail

Other Hospital

Name of Hospital

Address

Medical Record #

Hospital Operator Telephone

Emergency Department Telephone

Contact Person Name Title

Telephone Fax E-mail

Health Care Providers

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

Primary Care Provider

Name	Specialty (if any)
Clinic/Hospital Name	Telephone
Address	
Fax	E-mail

Medical Specialists and Health Care Providers

Name	Name
Specialty	Specialty
Address	Address
Telephone	Telephone
Fax	Fax
E-mail	E-mail
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
E-mail	E-mail
Clinic/Hospital Name	Clinic/Hospital Name
Frequency of Visits (how often)	Frequency of Visits (how often)

<u>Health Care Providers</u>

Name	Name
Specialty	Specialty
Address	Address
Telephone	Telephone
Fax	Fax
E-mail	E-mail
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
E-mail	E-mail
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
E-mail	E-mail
Clinic/Hospital Name	Clinic/Hospital Name
Frequency of Visits (how often)	Frequency of Visits (how often)

Other Health Care Providers

Use this form to list to service providers such as therapists, counselors, Early Intervention providers, care coordinators or case managers, personal care attendants (PCAs), respite providers, state agency contacts, etc.

Service(s)	
Agency Name	
Address	
Contact Person	Telephone
Fax	E-mail
Frequency of Visits (how often)	

Service(s)	
Agency Name	
Address	
Contact Person	Telephone
Fax	E-mail
Frequency of Visits (how often)	

Service(s)	
Agency Name	
Address	
Contact Person	Telephone
Fax	E-mail
Frequency of Visits (how often)	

Other Health Care Providers

Service(s)	
Agency Name	
Address	
Contact Person	Telephone
Fax	E-mail
Frequency of Visits (how often)	

Service(s)	
Agency Name	
Address	
Contact Person	Telephone
Fax	E-mail
Frequency of Visits (how often)	

Service(s)	
Agency Name	
Address	
Contact Person	Telephone
Fax	E-mail
Frequency of Visits (how often)	

Service(s)	
Agency Name	
Address	
Contact Person	Telephone
Fax	E-mail
Frequency of Visits (how often)	

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

Medications

Use this form to keep track of all medications your child takes. Include vitamins, over-the-counter medicines, and dietary supplements in the list. 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. (See below for example.) This way you have a complete record. You may also want to keep the drug information sheet with this information.

Medication Name	Dosage/Route (How much/how often? Mouth/g-tube?)	Reason for Taking drug	Start Date	End Date	Prescribing Doctor	Notes
[EXAMPLE] ~~Carnitor~~	~~5 ml 2x day (give at breakfast & lunch)~~	~~PA~~	~~3/15/06~~	~~3/31/06~~	~~Goldberg~~	~~Takes lunch dose at school~~
[EXAMPLE] Carnitor	10 ml 2x day (give at breakfast & lunch) 8am, 12pm	PA	4/01/06		Goldberg	Takes lunch dose(12pm) at school

Pharmacies

Tip: Insert authorization forms for prescriptions behind this page.

Main Pharmacy

Name

Address

Telephone

Fax

Hours of Business

Contact Person

Other Pharmacy

Name

Address

Telephone

Fax

Hours of Business

Contact Person

Mail Order Pharmacy

Name

Address

Telephone

Fax

Hours of Business

Contact Person

Supplies/Equipment

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

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

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

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

<u>Supplies/Equipment</u>

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

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

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

Description of Item and Item #	
Provider/Vendor Name	
Contact Person	Telephone
Prescribed by	Telephone
Reason Prescribed	
Contact Person for Service/Insurance Approval	Telephone
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

Home Health Agency

Agency Name

Contact Person Telephone

Address

Fax E-mail

Service(s) to be provided (for example, nursing, therapy, home health aides, etc)

Service	***Frequency (how often)***	***Amount (hours per visit)***
	visits/week	hours/visit
	visits/week	hours/visit
	visits/week	hours/visit
	visits/week	hours/visit
	visits/week	hours/visit

Notes/Comments

School/Day Care Center

Name of School

Address

Principal Telephone

School Nurse Telephone

Teacher(s) Telephone

Aide(s)

Special Education Contacts Telephone

Therapist(s) Telephone

School Psychologist Telephone

Guidance Counselor Telephone

Parent Advisory Committee (PAC) Contact Telephone

Is there a school-based health center at your child's school? π Yes π No

If yes, Name of Center Telephone

School Transportation (ie..bus service, taxi, etc..)

Agency Name

Driver Name

Contact Name Telephone

Address

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, babysitter, neighbors)

First	*Last*	*Relationship to me*

My Pets

My Pet is a _____ Name of Pet _____

My other pet is a _____ Name of Pet _____

All about Me

My "Favorites"

Toys _____

Games _____

Hobbies _____

Songs _____

TV Shows _____

Other _____

Things I like to do during my free time

_____

_____

Foods I like are

_____

_____

Foods I don't like are

_____

_____

I usually go to bed at _____o'clock.

Before bed, I usually

_____

_____

_____

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

_____

_____

Things I can do myself are

_____

_____

Date page completed_____

Birth and Development: About Mother's Pregnancy

Please describe any illnesses or problems during pregnancy.

Method of delivery π Vaginal π Caesarian π Breech π VBAC

Were there problems at delivery? π No π Yes

If yes, please describe

Mother's Obstetrician/Nurse Midwife _____ Telephone_____

Mother's Primary Care Provider _____ Telephone_____

Delivery Setting

Name of Hospital/Birth Center Telephone

Address

Was child transferred to another hospital? π No π Yes

If yes, Name of Hospital Telephone

Address

Birth and Development: About Your Baby

Birthweight _____lbs_____oz Length_____inches

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

Child's Apgar scores at 1 minute _____ at 5 minutes _____

Child's age at first discharge from hospital _____

Baby was fed π breast milk π formula If fed formula, list brand _____

Developmental Milestones

My Child	Age when he or she:	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 sentence		
Toilet trained		
Other:		
Other:		

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

Family Health History

Is there anyone in the family (parent, brother, sister, grandparents, aunt, uncle, cousin, etc.) with a similar disability or chronic illness? π No π 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	π Yes	π No	_____
2. Heart problems	π Yes	π No	_____
3. Developmental disability	π Yes	π No	_____
4. Seizure disorder	π Yes	π No	_____
5. Diabetes	π Yes	π No	_____
6. Blood disorder	π Yes	π No	_____
7. Cancer	π Yes	π No	_____
8. Vision and/or hearing impairment	π Yes	π No	_____
9. Stroke	π Yes	π No	_____
10. Other _____	π Yes	π No	_____

Has anyone in the family had genetic testing or counseling?
π Yes π No π Don't Know

If yes, please describe _____

_____

Diagnoses

Diagnosis Given	Provider who Gave Diagnosis	Date Noted	Notes

Allergies

Food, Drug, Other	Date of reaction	Reaction	Treatment	Outcome

Important Tests

Tip: Insert lab & test reports behind this section.

π Blood π X-ray π CT π MRI π Other _____ Date Performed
Description
Doctor who Ordered Test Telephone
Results
Location of Test Record Telephone
Comments

π Blood π X-ray π CT π MRI π Other _____ Date Performed
Description
Doctor who Ordered Test Telephone
Results
Location of Test Record Telephone
Comments

π Blood π X-ray π CT π MRI π Other _____ Date Performed
Description
Doctor who Ordered Test Telephone
Results
Location of Test Record Telephone
Comments

Important Tests

Tip: Insert lab & test reports behind this section.

π Blood π X-ray π CT π MRI π Other _____ Date Performed
Description
Doctor who Ordered Test Telephone
Results
Location of Test Record Telephone
Comments

π Blood π X-ray π CT π MRI π Other _____ Date Performed
Description
Doctor who Ordered Test Telephone
Results
Location of Test Record Telephone
Comments

π Blood π X-ray π CT π MRI π Other _____ Date Performed
Description
Doctor who Ordered Test Telephone
Results
Location of Test Record Telephone
Comments

Tip: Insert discharge summaries behind this section.

Hospital Stays

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

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

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

Hospital Stays

Tip: Insert discharge summaries behind this section.

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

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

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

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

Medical Bill Tracking Form

Date of Service	Provider	Amount Billed ($)	Insurance Paid	Date Paid	FamilyOwes (incl.co-pay)	My Payment/ date paid

Genetics

Contact Information

Metabolic Specialist:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Page Operator Number:_____

Genetic Counselor/Nurse:_____

Phone Number:_____

Fax Number:_____

E-mail_____

Other Specialists in Clinic:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

Clinic Visit

Appointment Date:_____
Appointment Time:_____
Labs Ordered:_____
Tests Ordered:_____

Questions:

_____
_____
_____
_____
_____

Notes:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Tip: Insert lab results behind this sheet.

Labs

DATE	TEST	RESULT	COMMENTS

Contact Information

Nutritionist Name:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Page Operator Number:_____

Other Nutritionist in Clinic:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

Nutrition Log

Name

Date

MEAL		FORMULA	PROTEIN	CALORIES	FLUIDS
BREAKFAST	Goal (Daily)				
SNACK					
LUNCH					
SNACK					
DINNER					
	Over Night Feedings				
TOTAL					

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

Metabolic Status Tracking Form

Month_____ Year_____

Day	Emesis (ccs)	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					

Formula Companies:

Ross Laboratories 1-800-258-7677
Propimex-1
Propimex-2
Prophree
Polycose Powder

Mead Johnson and Company 1-812-429-6399
OA1
OA2
PFD1
PFD2

Nutricia 1-877-482-7845
XMTVI Analog
XMTVI Maximaid
XMTVI Maximum
Duocal

Vitaflo USA 1-888-VITAFLO (888-848-2356)
MMA/PA Gel
MMA/PA Express
Isoleucine Amino Acid Supplement
Valine Amino Acid Supplement

Enteral Feeding Pumps:

Zevex 1-800-970-2337
Entralite
Infinity
2200

Tyco/Kendall 1-800-962-9888
Kangaroo 324
Kangaroo 2100 Pet
Kangaroo 524

Ross 1-800-258-7677
Embrace
Companion
Quantum
Patrol

Scale Retailers:
PKU of Illinois
630-415-2219
http://www.pkuil.org/Diet%20Management%20Product%20Order%20Form.pdf

Precision Weighing Balances
978-521-7095
www.balances.com

Scales Galore
1-800-832-0055
www.scalesgalore.com

Scalesonline.com
1-866-856-6100
ww.scalesonline.com

Low Protein Food Companies

Applied Nutrition
10 Saddle Road
Cedar Knolls, NJ 07927
1-800-605-0410
www.medicalfood.com
info@medicalfood.com

CamBrooke Foods
2 Central Street
Framingham, MA 01701
1-866-4-LOW-PRO
www.cambrookefoods.com
sales@cambrookefoods.com
baked goods contain propionic acid (calcium propionate/sodium propionate)

Dietary Shoppe
4436 Ridge Avenue
Philadelphia, PA 19129
215-242-53021-888-640-2800
www.dietaryshoppe.com
dietaryshoppe@juno.com

Dietary Specialties
10 Leslie CT
Whippant, NJ 07981

www.dietspec.com
info@dietspec.com

Ener-g Foods
5960 First Avenue South
P.O Box 84487
Seattle, WA 98124-5787
1-800-331-5222
www.ener-g.com
customerservice@ener-g.com

Glutino
1-800-363-3438
www.glutino.com

Lil's Dietary Shoppe
2738 W 111 ST
Chicago, IL 60565
1-773-239-0355
www.lilsdietary.com

Miss Robens
91 Western Maryland Parkway, Unit #7
Hagerstown, MD 21740
1-800-891-0083
www.allergygrocer.com
info@allergrocer.com

Nutricia
P.O. Box 117
Gaithersburg, MD 20877
888-566-7646
www.shsna.com

Med Diet Labs
3600 Holly Lance, STE 80
Plymouth, MN 55447
1-800-633-3438
www.med-diet.com
meddiet@med-diet.com

Specialty Food Shop
The Hospital for Sick Children
555 University Ave
Toronto, Ontario M5G 1X8
416-813-5294
www.specialtyfoodshop.com
sfs@sickkids.ca

Taste Connections
301-371-8861
www.tasteconnections.com
lopro@webuniverse.net

Tastee Apple
60810 County Road 9
Newcomerstown, OH 43832
740-498-8316
www.tasteeapple.com

Uncle Henry's Pretzels
1-800-683-8375
www.unclehenry.com

Pediatrician Section

Contact Information

Pediatrician Name:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Page Operator Number:_____

Nurse:_____

Phone Number:_____

Fax Number:_____

E-mail_____

Other Doctors in Office:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

Clinic Visit

Appointment Date:_____
Appointment Time:_____
Labs Ordered:_____
Tests Ordered:_____

Questions:

_____
_____
_____
_____
_____

Notes:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Labs

Tip: Insert lab results behind this sheet.

DATE	TEST	RESULT	COMMENTS

Cardiology

Contact Information

Cardiologist:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Page Operator Number:_____

Nurse:_____

Phone Number:_____

Fax Number:_____

E-mail_____

Other Specialists in Clinic:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

Clinic Visit

Appointment Date:_____
Appointment Time:_____
Labs Ordered:_____
Tests Ordered:_____

Questions:

_____
_____
_____
_____
_____

Notes:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Tests and Labs

Tip: Insert test & lab results behind this sheet.

DATE	TEST	RESULT	COMMENTS
EXAMPLE:	Echo Cardiogram	Normal	Retest in 12months

Gastroenterology (GI)

Contact Information

GI Specialist:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Page Operator Number:_____

GI Counselor/Nurse:_____

Phone Number:_____

Fax Number:_____

E-mail_____

Other Specialists in Clinic:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

Labs

Tip: Insert lab results behind this sheet.

DATE	TEST	RESULT	COMMENTS

Therapy Schedule

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday

Contact Information

Occupational Therapist:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Other OT's in Clinic that will work with my child:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Contact Information

Physical Therapist:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Other PT's in Clinic that will work with my child:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Contact Information

Speech Therapist:_____

Phone Number:_____

Pager Number:_____

Fax Number:_____

Address:_____

E-mail:_____

Other SLP's in Clinic that will work with my child:

Name_____
Phone_____

Name_____
Phone_____

Name_____
Phone_____

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

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.**

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 gene is, in essence, 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

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. www.nucdf.org
** 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

Master Forms

Event Diary

Use this sheet to keep track of important events related to your child's health that may happen from time to time. Some examples include vomiting, ketones, lack of energy, anything that would be abnormal for your child.

Date	Activity/Information

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

Important Information for a Sitter

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

I/We will be at I/We will be home around

Telephone Cell Phone Pager

Special instructions

Significant events during past 48 hours

Medications to be given and time(s)

In Case of an Emergency: CALL 911

Child's Name

Home Telephone Date of Birth

Address

Doctor's Name Telephone

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

Allergies

Extra equipment/supplies are located

Fuse box or breaker is located

Fire extinguisher is located

Flashlight is located

Medications

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

Phone Log

It is easy to lose track of what you discussed with providers when you have so many different phone calls about your child. Use this form to keep track of phone calls and other conversations you have about your child's health care.

Date and Time of Conversation	Name of Person and Agency	Phone Number	Notes (what was discussed or decided)

Meeting/Appointment Log

Use this form to keep track of meeting and appointments you have about your child's health care.

Date and Time of Meeting	Name of Person and Agency	Contact Information	Notes (what was discussed or decided)

CALENDAR

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

Clinic Visit

Appointment Date:_____
Appointment Time:_____
Labs Ordered:_____
Tests Ordered:_____

Questions:

_____
_____
_____
_____
_____

Notes:

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Tip: Insert lab results behind this sheet.

Labs

DATE	TEST	RESULT	COMMENTS

Nutrition Log

Name

Date

MEAL		FORMULA	PROTEIN	CALORIES	FLUIDS
BREAKFAST	Goal (Daily)				
SNACK					
LUNCH					
SNACK					
DINNER					
	Over Night Feedings				
TOTAL					

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

Metabolic Status Tracking Form

Month_____ Year_____

Day	Emesis (ccs)	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					