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- ☐ Final report
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- ☐ Web screen shot
- ☐ No report, publication, or study
- ☐ Deliverable pending
- ☐ OTHER material

If OTHER, please describe:

Accessing Coverage for Metabolic Formulas

A Toolkit for Families

Updated May 2017

MICHIGAN
FAMILY TO FAMILY
HEALTH INFORMATION CENTER

The Michigan Family to Family Health Information Center is a project of the Michigan Public Health Institute. It is funded by the Health Resources and Services Administration, Maternal and Child Health Bureau grant H84MC26214.

Accessing Coverage for Metabolic Formulas in Michigan
A Toolkit for Families

In the fall of 2013, the Michigan Department of Health and Human Services (formerly Community Health) brought together various stakeholders, including families, as part of the Diet for Life Work Group. The work group was charged with making recommendations to assure that patients of all ages with inborn errors of metabolism (IEM) continue to have lifelong access to appropriate metabolic formulas. Historically, the Newborn Screening (NBS) Program provided grant funding to the Children's Hospital of Michigan Metabolic Clinic to purchase formula for all children with IEM identified through screening. However, this is no longer possible due to increasing budgetary constraints.

One of the recommendations of the Diet for Life Work Group was to **maximize the use of third party insurance benefits for medical food and other nutritional treatments.** NBS program staff worked with several families to "test" insurance coverage for metabolic formulas in order to inform program policies before a requirement to use insurance coverage for formula was implemented. **Both children and adults with IEM are now required to use any available insurance benefits that provide coverage for metabolic formulas.**

The Michigan NBS Program has worked with public and private insurers to increase coverage. Michigan Medicaid and Healthy Michigan Plan cover metabolic formulas, and families with children under the age of 21 can enroll in Children's Special Health Care Services (CSHCS), which also covers formula. The NBS Program continues to provide safety net coverage in order to ensure that no one goes without necessary formula.

This toolkit was developed in an effort to assist individuals in understanding how to access insurance coverage for metabolic formula, and determining whether or not enrolling in CSHCS is cost-effective for their family.

Enrolling in Children's Special Health Care Services (CSHCS)

Enrolling in Children's Special Health Care Services (CSHCS) may be a good option for many families with children under the age of 21 who require metabolic formula. There may be a cost associated with CSHCS, so you need to determine whether or not CSHCS is cost-effective for your family.

Find out what your CSHCS Payment Agreement would be:

1. See the CSHCS Payment Agreement Guide in this toolkit to calculate what your payment agreement would be.

2. Using your recent medical receipts and bills you paid for your child(ren) with a metabolic disorder, fill out the Metabolic Condition Cost Calculator worksheet in this toolkit to estimate your yearly costs. Be sure to include the amount you were told is not covered by insurance when the Clinic places your formula order with the DME. Please note – this is only a worksheet to help you estimate your out-of-pocket costs. It is not part of the CSHCS's application process.

3. Compare the estimated CSHCS yearly payment amount with the total metabolic expenses you listed on the cost calculator worksheet to see if you would save money if your child enrolls in CSHCS.

How to Enroll in CSHCS:

1. Call the Metabolic Clinic social worker, and ask him/her to send a Medical Report to CSHCS.

2. You will receive a CSHCS enrollment packet in the mail.

3. Complete the packet and mail it in using the return envelope or to the address listed on the application. A CSHCS representative in your county health department can help answer any questions you might have about the application.

4. If you still have questions, call the CSHCS Family Phone Line at 800-359-3722 to speak with a parent who can help you.

PAYMENT AGREEMENT GUIDE

Children's Special Health Care Services

Michigan Department of Health and Human Services

This guide does not apply if the client has active full Medicaid, MIChild or Healthy Michigan Plan. If you checked any box in #7 on the MSA-0738, a payment for this client may not be required once documentation is verified.

This chart will give you the yearly payment agreement enrollment fee amount your family is required to pay to receive coverage by the Children's Special Health Care Services (CSHCS) program. If you have questions or need help, please contact a CSHCS representative at your local health department or call 1-800-359-3722.

INSTRUCTIONS: Use the information you put on your Income Review/Payment Agreement form MSA-0738:

- Find the column for the Family Size. Family size is the number of claimed exemptions you put on line #8 of the MSA-0738 form.
- Find the **Income Range** in this same column that includes the income you put on **line #9** of the MSA-0738.
- Follow the row across to the right to find your **Yearly Payment Agreement Enrollment Fee amount**.
- Put the **Yearly Payment Agreement Enrollment Fee amount** from the chart below on **line #10** of the MSA-0738.
- **Clients 18** or older are legal adults; therefore only their income is considered for line #9 and #10 of the MSA-0738.

If your yearly payment agreement enrollment fee is $120.00 (see chart below), your CSHCS coverage will be for 90 days. You will be required to also apply for Medicaid, MIChild, Healthy Kids or Healthy Michigan Plan coverage which provide additional comprehensive coverage. You must apply for Medicaid/MIChild/Healthy Kids/Healthy Michigan Plan for your CSHCS coverage to go beyond 90 days. If you do not apply in that 90 days, CSHCS coverage will end.

You will still be responsible for any CSHCS payment agreement enrollment fee that you sign even if CSHCS coverage is voluntarily ended, services are not used, the client ages out of the program, or the client moves out of the State of Michigan. CSHCS payments are non-refundable.

FAMILY SIZE / INCOME RANGE														
Family of 0-1	**Family of 2**	**Family of 3**	**Family of 4**	**Family of 5**	**Family of 6**	**Family of 7**	**Family of 8**	**Family of 9**	**Family of 10**	**Family of 11**	**Family of 12**	**Family of 13**	**Family of 14**	**Yearly Payment**
$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$0	$120.00
$24,119	$32,479	$40,839	$49,199	$57,559	$65,919	$74,279	$82,639	$90,999	$99,359	$107,719	$116,079	$124,439	$132,799	
$24,120	$32,480	$40,840	$49,200	$57,560	$65,920	$74,280	$82,640	$91,000	$99,360	$107,720	$116,080	$124,440	$132,800	$192.00
$30,150	$40,600	$51,050	$61,500	$71,950	$82,400	$92,850	$103,300	$113,750	$124,200	$134,650	$145,100	$155,550	$166,000	
$30,151	$40,601	$51,051	$61,501	$71,951	$82,401	$92,851	$103,301	$113,751	$124,201	$134,651	$145,101	$155,551	$166,001	$372.00
$36,180	$48,720	$61,260	$73,800	$86,340	$98,880	$111,420	$123,960	$136,500	$149,040	$161,580	$174,120	$186,660	$199,200	
$36,181	$48,721	$61,261	$73,801	$86,341	$98,881	$111,421	$123,961	$136,501	$149,041	$161,581	$174,121	$186,661	$199,201	$732.00
$48,240	$64,960	$81,680	$98,400	$115,120	$131,840	$148,560	$165,280	$182,000	$198,720	$215,440	$232,160	$248,880	$265,600	
$48,241	$64,961	$81,681	$98,401	$115,121	$131,841	$148,561	$165,281	$182,001	$198,721	$215,441	$232,161	$248,881	$265,601	$1,476.00
$60,300	$81,200	$102,100	$123,000	$143,900	$164,800	$185,700	$206,600	$227,500	$248,400	$269,300	$290,200	$311,100	$332,000	
$60,301 no ceiling	$81,201 no ceiling	$102,101 no ceiling	$123,001 no ceiling	$143,901 no ceiling	$164,801 no ceiling	$185,701 no ceiling	$206,601 no ceiling	$227,501 no ceiling	$248,401 no ceiling	$269,301 no ceiling	$290,201 no ceiling	$311,101 no ceiling	$332,001 no ceiling	$2,964.00

Metabolic Condition Cost Calculator Worksheet*

A. Metabolic Formula

Product	Cost per order	No. orders/year	Annual Cost

(A) _____
Total Cost/Formula

B. Prescriptions/Supplements for the metabolic condition

Product	Cost per order	No. orders/year	Annual Cost

(B) _____
Total Cost Rx and Supplements

C. Healthcare Provider Visits for the metabolic condition

Provider	Co-pay per visit	No. visits/year	Annual Cost

(C) _____
Total Co-pays

*This is a worksheet for your own records and decision-making, not part of the CSHCS application.

Metabolic Condition Cost Calculator Worksheet*

D. Out-of-Pocket Expenses for metabolic health care visits

(Depending on the family's needs, some potential benefits of CSHCS may include troubleshooting and help with transportation, fuel, overnight accommodations, etc.).

Date	Expense	Total Cost

(D) _____
Total for visits

Compare the total of all the estimated expenses you listed in Sections A - D with the *Yearly Payment Agreement Amount* to enroll in CSHCS.

This worksheet does not guarantee coverage of the expenses above. If you have questions about CSHCS, please call the Family Phone Line at **800-359-3722** to speak with a parent who can help you. Asking for more information does not mean you have to join the program.

Insurance

Please make note of rates for deductibles and co-insurance that could affect the amount you would need to pay out of pocket for your child's metabolic condition. Once a deductible is met, there may be an additional co-payment or co-insurance on items past that limit. You will need to read your insurance's policy agreement to understand if this applies to you.

Deductible amount: _____
Co-payment or co-insurance after deductible is met (*if applicable*): _____

*This is a worksheet for your own records and decision-making, not part of the CSHCS application. v.1-19-16

County Contacts for Local CSHCS Offices

Alcona
989-724-6757
ext. 1600

Alger
906-387-2297
ext. 105

Allegan
269-673-5440

Alpena
989-356-4507

Antrim
231-533-6255

Arenac
989-773-5921

Baraga
906-524-6142

Barry
269-945-9516

Bay
989-895-4235

Benzie
231-882-2108

Berrien
269-926-7121

Branch
800-482-9561
517-279-9561

Calhoun
269-969-6390

Cass
269-621-3143

Charlevoix
231-547-6523

Cheboygan
231-627-8850

Chippewa
906-635-3572

Clare
231-832-5532

Crawford
989-348-7800

Delta
906-786-4290

Dickinson
906-774-1868

Eaton
269-945-9516
ext. 115

Emmet
231-347-6014

Genesee
810-257-3146

Gladwin
989-426-9431

Gogebic
906-667-0263

Grand Traverse
231-995-6130

Gratiot
989-875-3681
ext. 1004

Hillsdale
800-482-9561
517-279-9561

Houghton
906-482-7382

Huron
989-269-9721

Ingham
517-887-4309

Ionia
616-527-5341

Iosco
989-362-6183
ext. 1500

Iron
906-265-9913

Isabella
989-773-5921

Jackson
517-788-4422

Kalamazoo
269-373-5200

Kalkaska
231-258-8669

Kent
616-632-7066

Keweenaw
906-482-7382

Lake
231-745-4663

Lapeer
810-667-0448

Leelanau
231-256-0200

Lenawee
517-264-5228

Livingston
517-546-9850

Luce
906-293-1324

Mackinac
906-643-1100

Macomb
586-466-6855

Manistee
231-723-3595

Marquette
906-475-5765

Mason
231-845-7381

Mecosta
231-592-0130

Menominee
906-786-4290

Midland
989-832-6673

Missaukee
231-839-7167

Monroe
734-240-7800

Montcalm
989-831-5237
ext. 3643

Montmorency
989-785-4428

Muskegon
231-724-6209

Newaygo
231-724-6209

Oakland
248-858-0056

Oceana
231-873-2193

Ogemaw
989-345-5020
ext. 1839

Ontonagon
906-884-4485

Osceola
231-832-5532

Oscoda
989-826-3970
ext. 1700

Otsego
989-732-1794

Ottawa
616-396-5266

Presque Isle
989-734-4723

Roscommon
989-426-9431

Saginaw
989-758-3845

St. Clair
810-987-6102

St. Joseph
269-273-2161

Sanilac
810-648-4098

Schoolcraft
906-341-9651
ext. 134

Shiawassee
989-743-2355

Tuscola
989-673-8114

Van Buren
269-621-3143

Washtenaw
734-544-6700

Wayne (Outside Detroit)
734-727-7088

Wayne (Detroit)
313-832-9342

Wexford
231-775-9942

Understanding Your Insurance Coverage

What's the difference between a Summary of Benefits and Coverage and a Certificate of Coverage?

The Affordable Care Act requires that health insurers and group plans provide enrollees with an easy-to-understand summary of their benefits and coverage, as well as a glossary of healthcare terms. This is called the **Summary of Benefits and Coverage,** and is usually no more than a few pages long. It explains the key features of a plan including covered benefits, cost-sharing provisions and limitations and exceptions. It also has to include coverage examples, which allow you to see what the plan would cover in a common medical situation. It is important to know that this document is only a summary, and does not contain all of the information you need to know regarding your insurance contract.

The **Certificate of Coverage** is the document that proves your insurance coverage and along with your signed application, serves as the contract between you and the insurer. Each health plan has a different certificate, because the benefits under each plan are different. The Certificate of Coverage is usually a very lengthy document and contains detailed information about eligibility, covered benefits, as well as a list of all items that are specifically excluded from coverage. In addition, the insurance plan may have **riders.** A **rider** is a document attached to the certificate that amends it in some way.

The Certificate of Coverage is not always distributed to consumers at the time they enroll in a new plan, but the insurance company must make it available to you. You should be able to access the Certificate onb your plan's website, or by calling the customer service number on the back of the card. If you get your health insurance from an employer, your employer is the policy owner and will have a master copy.

The Certificate of Coverage, complete with any riders, is the document you need to read in order to confirm what the insurance company must pay for under your plan. This is the contract, and will be the document that is referred to in the case of a dispute, or appeal.

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Glossary of Insurance Terms

Allowed Amount - Maximum amount on which payment is based for covered health care services. If your provider charges more than the allowed amount, you may have to pay the difference.

Appeal - A request for your health insurer to review a decision or a grievance again.

Affordable Care Act –The comprehensive health care reform act enacted in March 2010. Also referred to as the A.C.A.

Annual Limit - A cap on the benefits your insurance company will pay in one year. These caps are sometimes placed on particular services, or on the dollar amount or number of visits covered.

Balance Billing –When the provider bills you for the difference between the provider's charge and the allowed amount.

COBRA –A federal law that allows you to temporarily keep health coverage after your employment ends. If you elect COBRA coverage, you pay 100% of the premiums.

Coordination of Benefits– A way to figure out which insurance company pays first when two or more health plans are responsible for the same claim.

Co-insurance - Your share of the cost of a covered health care service, calculated as a percent of the allowed amount for the service (for example 20%).

Co-payment –A fixed amount you pay for a covered health care service, usually paid at the time of service (for example, $20 for a doctor's visit).

Deductible –The amount you pay for health care services before your health plan begins to pay.

Dependent Coverage –Insurance coverage for family members of the policyholder.

Durable Medical Equipment (DME) -Equipment and supplies ordered by a health care provider for everyday or extended use. Examples include: wheelchairs, feeding pumps, or blood testing strips.

Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT) -a term used to refer to the comprehensive set of benefits covered for children under Medicaid.

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Essential Health Benefits –A set of health care service categories that must be covered by most insurance plans under the Affordable Care Act.

Excluded Services –Health care services that your health insurance plan doesn't pay for or cover.

Flexible Spending Account –An arrangement you set up through your employer to pay out-of-pocket medical expenses with tax-free dollars.

Formulary –A list of prescription drugs covered by a drug plan. Also called a drug list.

Grievance –A complaint that you communicate to your health insurer or plan.

Habilitation Services –Services that help a person learn, keep or improve skills and functioning for daily living. Examples include physical and occupational therapy and speech therapy.

Health Savings Account –A medical savings account available to taxpayers enrolled in a high deductible health plan. The funds are not taxable, and unlike a flexible spending account, roll over year after year if you don't use them.

Medically Necessary –Health care services or supplies needed to prevent, diagnose, or treat an illness, injury, condition, disease or its symptoms and that meet accepted standards of medicine.

Network– The facilities, providers and suppliers your health plan has contracted with to provide services. Your share of the cost is lower if you use in-network providers.

Out-of-Pocket Costs –Your expenses for medical care that are not reimbursed by insurance. This may include deductibles, coinsurance and copayments plus all costs for services that are not covered.

Pre-existing Condition –A condition including a disability for which medical care was received prior to enrolling in a new health care plan.

Prior Authorization –A decision by your health care plan that a service is medically necessary. Your plan may require preauthorization for certain services before you receive them.

Referral –A written order from your primary care doctor for you to see a specialist or get certain medical services. In many cases, if you don't get a referral first, the plan may not pay for the services.

Rescission –The retroactive cancellation of a health insurance policy due to an omission or mistake on an application. Under the ACA, rescission is illegal.

What to do if your Health Insurance Claim is Denied

Review Your Coverage

You need to understand exactly what is covered under your policy so that you can determine whether or not you have grounds for an appeal. Insurance companies provide a Summary of Benefits when you enroll; however, you should read the actual policy itself. The document you need is called the Certificate of Coverage. Health plans are all different and each plan has a different Certificate of Coverage.

Find out why it was Denied

The insurance company should send you an Explanation of Benefits (EOB). You may get this in the mail, or you may have to access the information online. The EOB form states how much the insurer paid on a claim, or why it was denied. If you don't understand the explanation, or don't agree with it, call the insurance company.

Call your Provider

The procedure or service may have been coded wrong, and your doctor's office will have to resubmit the claim. It is important to let the provider's billing office know that you are aware the claim has not been paid and that you are working to resolve it. If they know you are working on it, they may waive late fees.

Keep a written record of any phone calls and/ or correspondence between you and the insurance company.

Learn the deadlines for appealing your health insurance claim denial. Find out what the insurance company's grievance procedure is.

Build your case.

Gather any documentation you need including medical reports, x-rays, and letters from the provider. Send a letter to the insurance company including all personal information, the date of service and the insurance claim number, stating concisely why you think the denial is wrong. Send the letter certified mail. Keep a copy for your records! Some insurance companies have an appeals form online.

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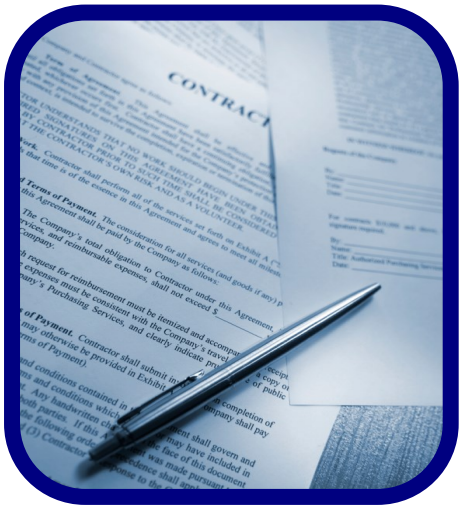
Try again.

If you claim is denied again after you have appealed it, try again. Find out why the insurer is saying no. You may need to submit more information. The insurance company is required to notify you of the next step in the grievance process. You may have the right to appear before a designated committee to present your case. You also have the right to authorize another person to act on your behalf.

External Review Process

If you still do not receive satisfactory resolution to your case, you can request an external review from the state. The Michigan Department of Insurance and Financial Services (DIFS) is the state agency responsible for regulating insurance companies. Michigan citizens are protected under the Patient's Right to Independent Review Act (PRIRA) and guaranteed a third party independent review. For information on how to request an external review, contact DIFS at 877-999-6442 or visit www.michigan.gov/difs to obtain a complaint form and instructions for filing it. DIFS will review your case, and make sure that your contract and all Michigan laws are being upheld.



Terms to Know

Appeal – a request for your health insurance plan to review a decision

EOB - Explanation of Benefits. The insurance company's written explanation of what it will pay for a claim

Grievance – a complaint that you communicate to your health insurer or plan

Policy - a contract between the insurance company and the policyholder which determines what claims the insurer is legally required to pay.

Summary of Benefits - a brief overview of the benefits provided by your insurance plan

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Children's Special Health Care Services (CSHCS)

FAQ For Families of Children With Metabolic Conditions

What is Children's Special Health Care Services (CSHCS)?

CSHCS is a program within the Michigan Department of Health and Human Services (MDHHS). It provides health coverage and support for children with eligible special health care needs and their families.

Is my child eligible for CSHCS?

Yes! Children under the age of 21 who need treatment with metabolic formula qualify. The child or family must also meet citizenship and MI residency criteria.

How can CSHCS help my child and family?

The coverage, support and services provided by CSHCS vary depending upon the child's or family's needs. Some potential benefits* of CSHCS for families of children with metabolic conditions **may** include:

- Payment of specialty medical bills required to treat the child's metabolic condition that are not covered by insurance.
- Coverage of copayment and/or deductibles related to the metabolic condition. This includes out-of-pocket charges for metabolic formula, clinic visits and related laboratory testing, and prescriptions for management of the condition.
- Troubleshooting and help with transportation to and from medical providers and clinic visits
- Coordination of medical services and community-based support services.

* *Please check with your local CSHCS office to determine how you would benefit.*

Are there financial eligibility requirements?

No. Financial information is not considered for CSHCS eligibility. Families of all income levels can enroll their children in CSHCS.

Is there a fee to join CSHCS?

Yes. Your family will need to complete an *Income Review/Payment Agreement* form that is included in the CSHCS enrollment packet. The amount a family is required to pay each year varies and is based on family size and income. There is no fee if your child is on Medicaid or MIChild.

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I have more than one child with a metabolic condition. Is there a fee for each child to join CSHCS?

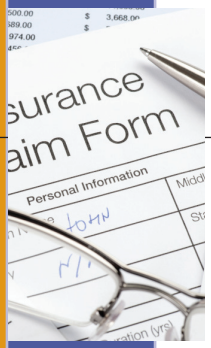
No. If more than one child is eligible for CSHCS, there is still only one payment agreement for that family.

What else should I consider to determine whether or not CSHCS would be financially beneficial to my family?

CSHCS may pay for more than just metabolic formula for your child. Other visits, treatments and services related to the metabolic condition may be covered as well. It is important to consider all of the out-of-pocket costs your family pays in caring for your child with a metabolic condition.

How do we apply for CSHCS?

Ask the social worker at your child's metabolic clinic to submit a medical report to CSHCS. Once medical eligibility is established, you will receive an application. For assistance with the application or understanding how CSHCS may be able to help your family, call **your local health department CSHCS office** or the **Family Phone line at 800-359-3722.** You can also contact the Family Center at cshcsfc@michigan.gov.



Chapter 14: Insurance Coverage for PKU Treatment

Insurance Overview

Medical foods (formula and foods modified to be low in protein) are a medical necessity for people with PKU. However, many adults and families face challenges in obtaining coverage from their health insurance.

Coverage for PKU-related medical foods varies from state to state, although 38 states have passed legislation that requires at least some coverage. Some states have passed legislation to mandate insurance coverage for medical foods, while others provide medical formula and some low protein foods directly to PKU patients through newborn screening or state health department programs.

To find information about legislation around insurance coverage of medical foods in your state, visit our state coverage resource tool at: http://npkua.org/index.php/state-coverage-for-pku[92].

If you are facing insurance denials, the National PKU Alliance may be able to help with its newly launched insurance ombudsman project. To learn more, visit http://npkua.org. Here you find additional information on the insurance appeals rights, your rights under the recently passed Affordable Care Act, as well as how to request a volunteer advocate to assist you with your cover issues. The first step to understanding your coverage for medical foods is to have a basic understanding of your health insurance plan.

Questions to Consider When Choosing a Health Insurance Plan

Many employers change health insurance companies on a frequent basis. This typically happens with the start of the benefits year. If you are facing this situation, it is critical that you be pro-active and work with your employer to try to ensure coverage of medical foods for PKU.

Questions to ask when your company informs you that they will switch health insurance companies:

- Who is the first point of contact for questions?
  - Your employer's HR Manager
  - A Benefits Consultant/Advisor hired by your employer, if offered
  - Toll free phone number for the insurance company
- Is the plan insured or self funded?
  - Under an insured plan, the employer purchases commercial health care coverage from an insurance company, and the insurance company assumes the risk for payment of claims. Insured plans are regulated by the individual states. If the plan is self funded, (often times called a "self-insured" plan), the employer keeps the risk to pay the bills and usually hires a plan administrator to process the claims. This differentiation is important because self funded plans are not subject to state insurance laws or regulations – a state cannot require a self-funded employer to cover PKU medical foods (formula and foods modified to be low in protein).
  - The best way to determine if the plan is self-funded is to ask the employer or call the plan. Generally, most very large employers and union plans self-funded.

[92] National PKU Alliance. "State Coverage for PKU." http://npkua.org/index.php/state-coverage-for-pku

Insurance Coverage for PKU Treatment

- Another way to determine if the plan is insured or self funded is to be aware of the documentation you receive. If your employer has an insurance policy, the plan is insured. If they have a plan document, the plan is self funded.
- Be aware that many self-funded plans use insurance companies to process their claims and perform other administrative duties. To further the confusion, the insurance company may also "rent" their provider network to the plan, so a self-funded plan may look very much like an insured plan.
- Sometimes self-funded plans are called "ERISA plans." ERISA is a very broad federal law that also regulates employer health plans. Don't be misled by this term - virtually ALL employer plans, whether they are insured or self-funded, are regulated by ERISA and technically are "ERISA plans." But generally, if a plan is called an "ERISA plan" it is probably self-funded.
- Another good way to determine if the plan is insured or self-funded is to read the documentation you receive. It may tell you directly if the plan is insured or self-funded.
- In addition, all ERISA-regulated plans are required to provide certain information to plan participants, but many employers with insured plans do not fully comply with this rule. The plan sponsor (usually the employer) is responsible for this, not the insurance company. Thus, if the employer has an insured plan, you may not see federally required information in the plan documents – typically missing would be the name of the "plan administrator", the designation of the plan's fiduciary, the plan year and plan number (used for federal reporting), and the plan name. If this information is missing, it's probably an insured plan.
    - Often your first point of contact at an insurance company will not know if there are state mandates. For example, when they first run a query, they will often get a message back stating that the formula is not covered because it is available over the counter. This can be disproven with just a few documents.
    - It may be necessary to submit your state's insurance coverage laws to the insurance company's appeals department in writing after your coverage begins. Current laws can be found on the NPKUA website at www.npkua.org under the legislation tab.
    - Be aware that private insurance companies may have different rules.
        - If your company opts for a self-insured plan, ask your company to work with you to ensure that formula is covered. Self- insured plans can design their own coverage spectrum and are not obligated to follow state mandates for coverage.
- Understand what benefit category medical foods fall under. Typically medical foods are covered either as a pharmacy product or a medical product. Some insurers may provide coverage for the formula, but not the foods modified to be low in protein.
    - Pharmacy benefit – your medical foods will be covered like a prescription drug and you will need to pay a monthly co-pay.
    - Medical benefit – your medical foods will be covered like Durable Medical Equipment (DME). The cost may be $0 per month or a percentage to be determined, after the deductible is met.
- In some instances the insured will pay out a percentage of the cost and be reimbursed.
- Some plans also establish annual benefit maximums.

Insurance Coverage for PKU Treatment

- What choices are available for plans? Does one meet your needs better than the others?

o Three plans are often offered:
  - HMO – (Health Maintenance Organization) plans are often the most restricted and some may not cover medical foods.
  - POS - (Point of Service) plans usually provide good coverage but with limited choice of providers.
  - PPO - (Preferred Provider Organization) plans are sometimes the least restrictive in terms of both coverage and choices.

It's important that you do the math. Find out the contribution to the premium for each plan. This contribution is the amount of money you pay to an insurance company for insurance coverage. It is important to note that even if a certain plan has a lower contribution (meaning you will be paying less each month for your insurance coverage), it may mean you have to pay more out of pocket for medical services. So if you are going to be accessing healthcare often, it may be worthwhile to pay a higher premium up front to get better coverage later when you need it most. Consider the following scenario:

- Standard Plan- Biweekly premium $100 or $200/mo. Benefits pay 50% of medical food costs. Medical formula is $1200/mo. You would pay a total of $800/mo ($200 for insurance and $600 for formula) under this plan.

- Premium Plan- Biweekly premium $200 or $400/mo. Benefits pay 80% of medical food costs. Medical formula is $1200/mo. You would pay $640/mo.($400 for insurance and $240 for formula) under this plan.

  - o If an itemized benefits package is not handed out, request one and read it over. Pay close attention to sections relating to the needs of PKU: pharmacy copays, Durable Medical Equipment coverage, and specialist doctors. If it is unclear you can ask your first point of contact for clarification or more details.
  - o If none of the plans meet your needs, it doesn't hurt to ask for more options. It is not unheard of for an HR Manager in a small company to make changes to better meet the needs of the employees.
  - o Find out if there is a Flexible Spending Account available. Your deductible and copays can be tax-free if planned out in advance. Keep in mind that these accounts do not roll over into the next year.
  - o If your needs allow, you may find it beneficial to opt in to a Health Savings Account. These are similar to a Flexible spending Account in that they are not taxed, but may require you to choose a very high deductible plan. A benefit is that they do roll over at the end of the year. A Health Reimbursement Plan is similarly not taxed, but may not roll over year to year.
  - o Know your expenses. Keep a record of how much you spend on PKU products per month and per year to help you determine which plan fits your needs best.

- Is your preferred PKU clinic in-network?
  - o If not, contact your clinic and ask if they can try to join the network, or if they already have a plan for such situations. You can also ask the plan for an "out of network" exception.

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Documentation to have available:

- Soft and hard copy of your state's legislation regarding coverage for medical foods.
- Proof of prior coverage (will be sent by previous insurance company within 30 days of cancelation of coverage).
- Contact information for your previous insurance company, as well as your old group number, individual ID number, and toll free phone number (ID card or copy of both sides).
- Copy of your prescription for medical foods.
- Full name of your formula and manufacturer contact information.
- PKU quick facts sheet: description, diagnosis, symptoms, treatment, etc.
- Send your clinic your new health insurance information as soon as possible. Your new insurance company may require correspondence with your clinic to approve your formula coverage. It is much easier to get assistance from your clinic if they have had time to prepare for the near-inevitable request for Letters of Medical Necessity (see Appendix A).

Other Tips

- Your HR Manager or benefits consultant may request a list of your diagnoses and treatments, including all prescription products and procedures required. This helps them determine how to help you get the best coverage option. If they don't ask for it you may offer it.
- The internet and search engines can be a valuable research tool to find information about health insurance companies, look up terminology, and reach out to your PKU communities for support.

Understanding Your Current Health Insurance Plan

In order to learn about your current coverage, or if you receive a denial for medical foods coverage, you need to get a copy of your master insurance policy (for insured plans) or the plan document (for self funded plans) and read it. If you have a self funded plan, ERISA requires that the plan administrator (generally the employer) provide this documentation within 30 days of a request. Many employers don't know they are required to do this and will often tell employees that they don't have anything. Sometimes people think they have 100% coverage for all prescriptions, services and medical foods, just because they have insurance. This is not true[93]. It's important to read your coverage document carefully.

- Find out if medical foods for PKU are a covered benefit and if you will be responsible for any co-payments, co-insurance and/or other deductibles[94].
- If medical foods are covered, you need to learn whether they are a medical benefit or a prescription benefit. This determines who will supply the formula. If your formula is covered under the prescription part of your benefits, then you can have your prescription filled at an approved pharmacy. If your medical food is covered under the medical part of your benefits then you will need to have a medical supply company provide the formula. To find an "In-Network" pharmacy or medical supply company, ask the insurance representative for a provider list or contact your metabolic team and/or the formula manufacturer[95].
- If you are a federal employee and have insurance through the Federal Health

[93]Maltzman, S, : *My PKU Toolkit A Transition Guide to Adult PKU Management.* New Jersey: Applied Nutrition Corp. , p. 50.
[94]Maltzman, S, : *My PKU Toolkit A Transition Guide to Adult PKU Management.* New Jersey: Applied Nutrition Corp. , p. 50.

Employee Benefits (FEHB), medical formula is normally covered for children up to the age of 26. Foods modified to be low in protein are normally not covered. In addition, it's important to know that federal plans do not have to follow any state or most federal mandates for coverage.

- If you are on Medicaid, your formula should be covered and foods modified to be low in protein should be covered as part of the Early and Periodic Screening, Diagnostic and Treatment program as a health benefit under medical supplies.
- Contact your HR manager at work to learn if your health insurance plan is a self-insured plan. This will help you determine whether or not your plan has to follow any mandates that exist in your state regarding coverage for medical foods. ERISA prevents many adults and families from getting coverage for medical foods despite these state laws. Self funded plans can design their own coverage spectrum. In many cases, these plans choose to exclude medical foods for the treatment of PKU from their coverage. Many companies provide a self funded plan to their employees because it costs less to do so. If your employer moves from an insurance plan to a self-funded plan, they will often maintain the same benefits. They will often not remove the coverage until they find out they have large claims, but it is a violation of The Health Insurance Portability and Accountability Act (HIPAA) to remove benefits for a particular condition that a participant is being treated for.
- You still have a right to appeal a denial for medical foods coverage if you have a self funded plan. See the section on Appeals Process for more information.

Letter of Medical Necessity

In order to obtain insurance coverage or appeal a denial, you will need a letter of medical necessity from your doctor. The letter should detail your specific needs for medical foods and laboratory coverage as treatment for your PKU condition. It should also clearly state why these treatments are necessary for managing your PKU. A sample letter of medical necessity can be found in the resources section.

Dealing with Your Insurance Company [96]

To get the maximum coverage for medical foods to which you are entitled, you need to contact your insurance company. Call the member/customer service number on your insurance card and ask for the benefits department to find out if a prior approval is required. Always write down the name of the person with whom you spoke, the date and any information discussed. If the representative won't give out personal information, get his/her first name, ID number or direct phone extension, at the very least.

Inform the representative of your needs. Be sure to provide him/her with the product name, description, national drug code (NDC), HCPCS code, and manufacturer name and phone number. These codes can be located by calling the manufactuer of your medical food. Explain that you need this product for the dietary management of Phenylketonuria (ICD-9/ diagnosis code: 270.1), which is an inherited disorder of metabolism and that this product is medically necessary for your treatment. Specific information in commonly used codes can be found in Appendix B.
Your insurer should be able to tell you if medical foods are a covered benefit and whether

[96]Maltzman, S, : *My PKU Toolkit A Transition Guide to Adult PKU Management*. New Jersey: Applied Nutrition Corp. , p. 51.

or not you will need prior approval for coverage. If you do need prior approval, find out where to fax or mail the copy of your state law, prescription and letter of medical necessity to obtain a prior approval number. Keep records of any fax transmittals and return receipt via mail.

Sometimes the insurance representative may not be familiar with the policies regarding medical foods. If this is the case, ask to speak with a supervisor or case manager and begin again. At this point it may be helpful to mention that there is a state law that mandates coverage (if one exists in your state).

Keep an insurance file where all of the paper work, documentation and receipts can be kept for future reference. You can also request a case manager from the insurance company. Most insurance companies provide case management services for people with chronic health issues. A case manager can prove to be very helpful in navigating the insurance benefits.

Flexible Spending Accounts

A Flexible Spending Account (FSA) is an employer-provided benefit that allows employees to set aside income from their paychecks to pay for medical expenses. The major benefit to FSA account holders is that this income is not taxed, saving both money on income taxes as well as increasing the amount of money that can be spent on medical expenses (as it is actual income, rather than taxed income).[97]

If you have medical food expenses that are not covered or partially-covered by your insurance company, an FSA can be a convenient way to save money over the course of the year from your paycheck. Usually you will determine how much money should be allocated from your paycheck into your FSA at the beginning of each year. Generally, only the cost of foods modified to be low in protein that exceed the cost of normal foods can be reimbursed.

Not every employer has an FSA benefit. Talk to your employer or benefits administrator about your employer's FSA plan and how it could work for you.

What is ERISA?

The Employee Retirement Income Security Act of 1974 (ERISA) is a federal law which is primarily concerned with pension plans. However, it also sets minimum standards for many employee benefits, including employer provided health coverage.

ERISA governs approximately 2.5 million health benefit plans sponsored by private employers nationwide. It does not apply to government and church employee plans.

ERISA plans are not subject to state insurance laws or jurisdiction. Thus, even in your state has a law requiring some sort of coverage for medical foods, if your plan is self-funded, is does not have to follow the state law. This called an ERISA exemption.

Insurance Resources

National PKU Alliance: The NPKUA works to improve the lives of individuals with PKU and pursue a cure. This tool-kit is part of our Insurance Ombudsman Initiative to provide information and support to adults and families struggling with insurance

[97]FSAFeds. "What is a Flexible Spending Account?" https://www.fsafeds.com/fsafeds/summaryofbenefits.asp#WhatIsFSA

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coverage for medical foods. A central part of this new program will be to offer support and guidance through a network of lay advocates. www.npkua.org

The Patient Advocacy Foundation: This foundation provide pro bono case management and insurance mediation assistance for those with chronic, debilitating, or life threatening diseases. They may be able
to provide assistance to PKU adult and families.
www.patientadvocate.org. 1-800-532-5274.

Nutricia Product Coverage Navigator: Nutricia's program in Massachusetts, New York and Texas provides assistance to families using their metabolic products. They can provide assistance with prior authorizations, claims submissions, medical necessity letters, billing errors and the appeal process. 1-800-356-7354, ext. 1200.

Resources are available to support you in managing phenylketonuria (PKU) and its treatment. First, and most importantly, your PKU team is always available to support you as your primary support and source of information. Resources have also been developed and refined over the years to help you. Here we provide you with samples and direction to other resources that will continue to support you with managing PKU from infancy through to adulthood.