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DEPARTMENT OF HEALTH AND HUMAN SERVICES  
LANSING

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January 19, 2016

Subject: Metabolic Formula – Changes in Coverage for Patients (under Age 21)

Dear Metabolic Clinic Patients and Families:

You may recall we sent you a letter in the fall of 2014 about the need to find new funding sources to pay for metabolic formula. We formed a Metabolic Formula and Food Family Work Group in 2015 to find out what may happen when families no longer get free metabolic formula. Results from the work group (enclosed) helped the department think through the changes.

As of October 1, 2016, the Newborn Screening Program can no longer pay for metabolic formula for children and youth under 21 years of age. At that time, you will need to use your insurance or pay out of pocket. If you are on Medicaid, your formula is already being billed to Medicaid.

We want to allow families with private insurance time to decide what to do about this change. Starting in January 2016, the Metabolic Clinic will work with a Durable Medical Equipment company (DME) to test your insurance coverage for your next formula order. Please call your dietitian at least two weeks before you need your formula. It is important for every family to test their insurance benefits by April 1, 2016.

If your insurance pays for the total cost of metabolic formula, the DME will order and get the formula to you. If your insurance does not cover all or a majority of the cost of formula, it can still be provided by the clinic until September 30, 2016 but you need to explore your options. You may want to consider joining the Children's Special Health Care Services Program (CSHCS) to help cover the cost of formula. A CSHCS FAQ and other information is enclosed. Children and youth (under age 21) who need metabolic formula are eligible for CSHCS.

From the work group we learned that patients will likely fit into one of four groups:

1. **Patients with full Medicaid coverage.** Their Medicaid benefit will pay for metabolic formula with no cost to the family.
2. **Patients with private insurance.** The metabolic formula will need to be charged to their insurance. The insurance company may:
  - a. Cover the full cost of formula with no cost to the family.
  - b. Cover some of the formula cost. Family would have to pay remaining cost.
  - c. Not cover any of the formula cost. Family would have to pay the full cost.
3. **Patients with or without private insurance who also enroll with CSHCS.**
  - a. There is no cost to the family for metabolic formula or other condition-related medical care.
  - b. There is an annual fee to enroll with CSHCS. See the enclosed "Steps to Take" document for more details.

4. **Patients with no insurance, who do not wish to enroll in CSHCS.** Family will have to pay the full cost of metabolic formula.

The Michigan Family to Family Health Information Center will offer training and information to help families deal with the change to insurance billing, including insurance co-pays and deductibles. They may also be able to help with other needs. If you want to be notified of dates for trainings, either in-person or by webinar, please contact Jane Pilditch at [jpilditc@mphi.org](mailto:jpilditc@mphi.org) or 517-324-8391.

Information regarding inborn errors of metabolism is also posted at [www.michigan.gov/IEMtreatment](http://www.michigan.gov/IEMtreatment). This is sometimes referred to as "Diet for Life".

Thank you for your understanding as we try to ensure Michigan residents living with inborn errors of metabolism are able to get the needed formula. If you have questions, please feel free to contact us at [newbornscreening@michigan.gov](mailto:newbornscreening@michigan.gov) or call 866-852-1247.

Sincerely,



Sarah Lyon-Callo, MA, MS  
Director, Lifecourse Epidemiology and Genomics Division

SLC:vg

Enclosures

cc: Children's Hospital of Michigan Metabolic Clinic  
DHHS Children's Special Health Care Services Program  
DHHS Medical Services Administration  
Family to Family Health Information Center