Children born with phenylketonuria (PKU) and other rare inherited metabolic disorders will suffer permanent, profound disability or death unless their conditions are detected shortly after birth, before symptoms appear. With early detection, treatment with specialized Metabolic Treatment Products can prevent the otherwise catastrophic consequences of these conditions.

To assure early and timely detection, the Department of Health (DOH) Newborn Screening Program tests every baby born in Washington for these conditions. To assure that those affected have reliable, consistent access to the unique products necessary to prevent serious health outcomes, DOH operates the Metabolic Treatment Products (MTP) Program. The program purchases, stores, and distributes the products to those who need them.

The program is funded primarily from charges that cover the cost of purchasing and distributing these products. For non-Medicaid clients, the cost of providing these products is recovered by charging the family’s health care payer. For those individuals whose health care payer is Medicaid, DOH helps offset the difference between the cost and reimbursement from Medicaid. Despite recent changes to Medicaid reimbursement, there remains substantial underpayment for most of the products. To make up for the difference, and to allow DOH to continue serving this vulnerable population, $160,000 per year of GF-S is available to DOH.

**Services**

- As of April 2014, about 210 patients are being served by the MTP Program. About 80 (40 percent) have Medicaid as their source of medical funding.
- In the 2013 biennium, the cost for providing the service to all patients was $1,794,000. Of this, the GF-S accounted for $263,000, or about 15 percent.

**Stakeholders**

- Families on Medicaid who depend on MTP to prevent disability or death from these conditions
- Physicians who provide care for newborns and those found to have one of these conditions
- Washington citizens and citizen groups that care about the well being of children and preventing disabilities. For example:
  - The ARC of Washington
  - The March of Dimes
  - The PKU Action Group
  - Save Babies Through Screening
- Washington citizens who benefit from the dramatic reduction in health and disability care costs by preventing the consequences of these conditions
Recent Funding History

2007-09 biennium:
- Received $260,000 increase in GF-S funding to replace the loss of federal reimbursements.