

Access to Treatment:

A Parent's Perspective

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Survey on Access to Treatment

- Brief questionnaire sent out on support group list serves (no pilot)
- Received 60 responses from 31 states
- Disorders represented include: Phenylketonuria (PKU), Propionic Acidemia, Methylmalonic Acidemia, Homocystinuria, Glutaric Acidemia, Tyrosinemia Types I and III
- 80% of responses from individuals with PKU or parents of children with PKU

Who pays for your or your child's medical food?

- 56.7% affected individual/family (34)
- 16.7% insurance (10)
- 10% insurance/family (6)
- 8.3% state/family (5)
- 3.3% state general (2)
- 1.7% newborn screening program (1)
- 1.7% no one (1)
- 1.7% N/A (1)

Who pays for your or your child's medical formula?

- 40.0% state general (24)
- 33.3% insurance (20)
- 16.7% insurance/family (10)
- 3.3% affected individual/family (2)
- 3.3% state/family (2)
- 1.7% newborn screening program (1)
- 1.7% no one (1)

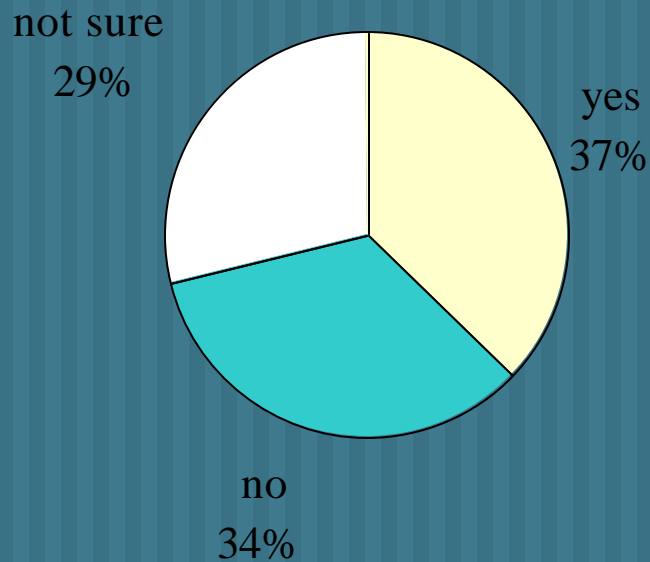
Who do you think should pay for medical food?

- 41.7% insurance (25)
- 25.0% insurance/state (15)
- 8.3% not sure (5)
- 6.7% affected Individual/family (4)
- 6.7% newborn screening program (4)
- 3.3% newborn screening program/state (2)
- 1.7% federal government (1)
- 1.7% federal government/insurance (1)
- 1.7% family/insurance/state (1)
- 1.7% family/insurance (1)
- 1.7% state (1)

Who do you think should pay for medical formula?

- 47.5% insurance (28)
- 18.6% insurance/state (11)
- 10.2% newborn screening program (6)
- 8.5% state (5)
- 6.8% insurance/newborn screening program (4)
- 3.4% newborn screening program/state (2)
- 1.7% federal government (1)
- 1.7% federal government/insurance (1)
- 1.7% family/insurance (1)

Is there an insurance mandate in place in your state?



Respondents' Concerns:

- Reimbursement system is financial strain
- Claims repeatedly denied
- Financial strain of co-pays and deductibles
- Insurance mandates do not help the uninsured, nor those who fall under ERISA
- Age and disorder specific limitations of mandates and state programs