

P.S. I talked with 3 Kansas doctors about this, and they support the proposed change.

To: the Senator
From: Mary
Date: July 28

We've been contacted by the American Academy of Pediatrics who would like your support for their proposed modification in the WIC program. The changes which they propose would affect about 2,000 children who have one of 4 rare genetic inborn errors of metabolism. The disorders are phenylketonuria (or PKU, and which includes most of the children), maple syrup urine disease, homocystinuria, and tyrosinosis.

Children who were born with any of these disorders require a special nutritional formula, and if proper care is given soon enough to the children, then the chances are pretty good that they will have a normal life. PKU victims must take the formula for about the first 5 years, and then they can usually go off of it. If they don't receive the formula, then they become little more than idiots, and must be institutionalized.

The Academy has proposed 2 changes in the administration of the WIC program to meet the needs of these babies. Although the special formula is allowed on the WIC program, it is allowed only through the first year, like the regular infant formula, and then the babies are switched to solid food. However, the PKU babies can't take the food, and must continue on the formula. Anyway, the Academy would like for babies with this disorder to be allowed to continue on the formula until they must go off the WIC program.

Also, the Academy proposes that this special formula be distributed through the state genetic centers (which are already established) rather than through the WIC health centers. This is so that the infants can receive the special treatment and attention which their condition requires. Although these diseases are treated solely by dietary management, it still requires careful surveillance, or the results are severe mental retardation or death.

USDA is to make a ruling fairly soon on this proposal, but they would not tell me their present position on it. Would you like to write a letter indicating your support of this program modification, if you do support it? Although the formula is costly, the number of children involved is so small that the extra expense should be absorbed by the rest of the program.

Yes, I support this, so go ahead and write _____
No, don't write _____