

### Submission - Labelling review recommendation 17

Thank you for the opportunity to comment on the recommendation that the declaration in the nutrition information panel of amount of nutrients per serving be no longer mandatory unless a daily intake claim is made. The recommendation proposes that the only requirement should be to provide the amount per 100grams or 100mls, while still permitting manufacturers to provide per serving information voluntarily.

My child lives with a rare medical condition known as an Inborn Error of Metabolism (IEM). It is imperative to our daily intake of nutrients to have the nutritional panel clearly stating the per serve column. IEM disorders require daily monitoring and measuring of what food is consumed every day under supervision of specialised metabolic health professionals. Without adhering to a strictly medically controlled diet for life the effects on my child would be devastating resulting in irreparable neurological damage and in some cases liver failure and death.

Below is my submission as to why I would **NOT** support this recommendation to have the per serve no longer mandatory on the nutritional panel.

The NIP is extremely important to me and must remain on packaging because;

- Helps maintain correct daily measurement of ☐ Protein
- ☐ Carbohydrates
- ☐ Fats
- Daily dietary intake will not be compromised due to calculation errors. Research shows that children who have chronic conditions do best at lifelong compliance if they are given independence managing their condition as early as possible.
- The per serve column is simplistic for caregivers/older children in assisting with counting of dietary intake. I have educated my child to read the per serving calculations which assists to adhere to their daily allowance.
- My child's health and quality of life is more important than Recommendation 17 which aims to reduce the regulatory burden on industry of formal cost-benefit analysis.

#### Comments:

My child has a metabolic disorder called Phenylketonuria (PKU) which means his body cannot break down the amino acid phenylalanine which is found in protein causing it to build up in his brain and cause significant neurological damage. To manage this condition he is given a low protein diet which excludes all meat, seafood, milk, cheese, eggs, nuts, legumes, tofu, soya, pasta, rice and products made with flour. He is required to take a special formula three times a day which contains nutrients, fats and amino acids that cannot be obtained through the diet.

He is currently on a daily total of 7g of natural protein which is to be divided over the meals of the day. To put it in perspective a single 25g portion of cheese is 5.9g per serve which is what someone

on a normal diet would have as part of a meal. His diet consists of fruits, vegetables, specially formulated low protein products and some commercial products found in the supermarkets. These are either counted as free or counted towards his total with anything less than 0.3g of protein per serve considered to be free.

Food labels are incredibly important to us as we use them many times a day to calculate the protein, energy, fat and salt content so we are able to maintain correct protein intake for our son and make healthy choices for him. We are currently teaching our son to read the information provided on food nutritional labels to help encourage independence with his diet. Research has shown that by teaching children from a young age, it helps them create a positive attitude towards food and their diet and encourages adherence to the diet for life.

Food not only provides nutrition to our body but is also used in many social situations, celebrations and is an important part of the human culture. The PKU diet is very restrictive and it takes a lot of time and planning to adhere to it leaving little space for spontaneity. The removal of the per serve information would be a huge disadvantage to the Metabolic community. It would remove the ability to determine protein content at a glance which could lead to miscalculations and further restrictions on an already limited diet.

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Signature: *ML Leahy* *RS Leahy*

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