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NSPKU, the national charity for the rare disease phenylketonuria (PKU), has raised concerns that the Soft Drinks Industry Levy discriminates against people with the disease. The Levy encouraged manufacturers to reformulate drinks to lower the sugar content, and in practice the majority of drinks have been reformulated with the artificial sweetener aspartame.

Aspartame is converted into phenylalanine in the body. People with PKU are unable to metabolise phenylalanine, which builds up in the blood and brain. Aspartame is therefore known to be harmful to be people with PKU.

NSPKU have informed the government that:

-Following the introduction of the Levy, people with PKU were at risk of accidentally consuming aspartame as manufacturers introduced aspartame into products without obvious warnings or changes to packaging. Ingesting high levels of phenylalanine is potentially very damaging in people with PKU, particularly children.

-Although legislation requires food or drinks to be labelled with ‘contains a source of phenylalanine’, patients do not necessarily check each time they consume a product. The warnings are very difficult to read, especially for children and vulnerable adults. They are also inaccessible in some situations such as vending machines and drinks dispensers.

-People with PKU do not have a choice of drinking diet drinks with aspartame. As the majority of drinks have been reformulated with aspartame, they are likely to be forced to pay the Levy in order to have a soft drink.

-People with PKU eat an extremely restricted medical diet in which almost all normal foods are banned or eaten in very limited quantities. Sugar based drinks are one of the few readily accessible treats for people with PKU. Patients may also use sugary drinks as a way of increasing their calorie intake and stabilising their phenylalanine levels within safe limits. The Levy therefore has a disproportionate impact on people with PKU.

NSPKU noted that the Levy was introduced without any targeted consultation of people with PKU. There was no consideration of the risk of harm or the disproportionate impact on people with PKU.

NSPKU have asked the government for assurances that it will monitor the effect of the Levy on people with PKU and consult appropriately in relation to any extension of the Levy.

Eric Lange, Chairman of NSPKU said “PKU is a rare disease but people living with this condition should be considered when creating government policy. It is regrettable that the Soft Drinks Industry Levy has created an additional challenge and restriction for people that already live with a difficult condition."

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