



Galactosemia Foundation Conference 2012

Diet Update

As a disclaimer, please note that the information presented below in relation to diet is presented for discussion only and that the AGSN supports the current recommendations made in the Handbook for Galactosaemia produced by ASIEM. You should always discuss any diet matters with your healthcare providers before making any changes.

Changes in the US diet

The US is moving to a more liberalised diet. This diet will allow patients to consume all fruits and vegetables, cheeses matured for 12 months or longer (including parmesan cheese), all beans and lentils (including chickpeas) and soy sauce. This new diet will also allow consumption of caseinates (such as calcium caseinate and sodium caseinate), which are used in many products as a binding agent or thickener.

Reasons for change

There are a few reasons for these changes. The main reason is simply that although these foods contain higher galactose than some other foods, the levels of galactose are still relatively low when compared to milk and other dairy products. For example, studies have shown that 100g of kidney beans contains approximately 150mg of galactose compared to 100mls of cow's milk which contains approximately 2,350mg of galactose. 100g of boiled chickpeas contains 444mg of galactose (including galactose present in the water used to boil the chickpeas which would not ordinarily be consumed if the chickpeas were eaten). A tablespoon of fermented Kikkoman soy sauce has been shown to contain 31mg of galactose. It was mentioned at the conference that many of the more experienced clinics in the US adhere to this new diet. However, others are still considering what changes (if any) they will make.

Gal-1-P levels and diet mistakes

Presenters at the conference mentioned that Gal-1-P levels will fluctuate significantly in the short period after consumption of high galactose foods. For example, if a person with galactosaemia were to mistakenly drink a glass of milk or eat a milk based ice-cream, their Gal-1-P levels would usually be significantly higher for a period of approximately 24 hours. However, after this time, the levels would be expected to return to the lower levels ordinarily found in that person when they are maintaining their low galactose diet. Doctors do not think

this short-term spike in Gal-1-P levels has any impact on the symptoms experienced by that person and that, although the diet does need to be maintained, a small mistake here and there is not a major problem. Most likely, the person would experience stomach discomfort due to the fact that their body is not used to processing high lactose foods.

Given the fluctuations in Gal-1-P levels, and the fact that these fluctuations do not appear to make any difference to long-term outcomes, some doctors in the US are now questioning whether regular Gal-1-P testing is required. They are still doing more research on this in the US and have not formally changed their policies. It is interesting to note that in Australia regular Gal-1-P testing is no longer standard practice throughout the country.

An alternative to Gal-1-P testing is urine based testing of galactitol levels. Galactitol testing is widely used in research projects relating to galactosaemia and is a more reliable indicator of galactose levels, as it would be affected by galactose intake during the month before the test rather than the 24 hours before the test (which is the case with Gal-1-P blood testing).

Vitamins and supplements

It was mentioned at the conference that calcium supplements are of benefit to people with galactosaemia and that a majority of patients regularly take these supplements. Vitamin D supplements can also help with calcium absorption. Good sources of Vitamin D include tuna, mackerel, orange juice and salmon. Good sources of calcium include dry cereals, sardines, soy milk, orange juice and green vegetables. Interestingly, research has shown that on fruit fly populations Vitamin C can have a positive effect and studies are continuing to see whether this will also be of benefit to humans. At this stage there is no recommendation that Vitamin C supplements are given to people with galactosaemia, but this may change in the future.