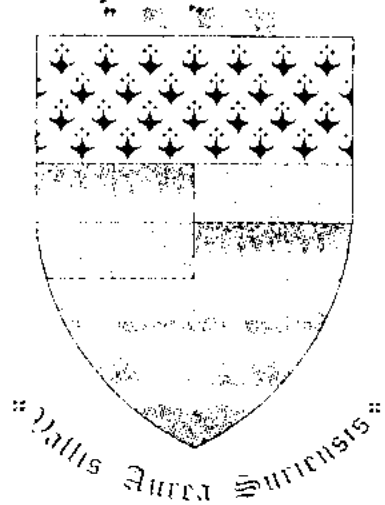


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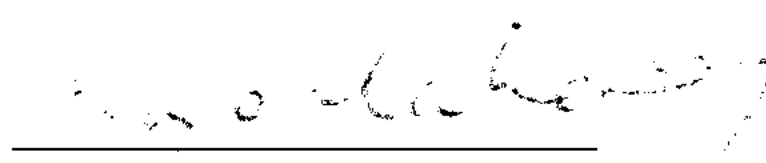
4th October, 2006.

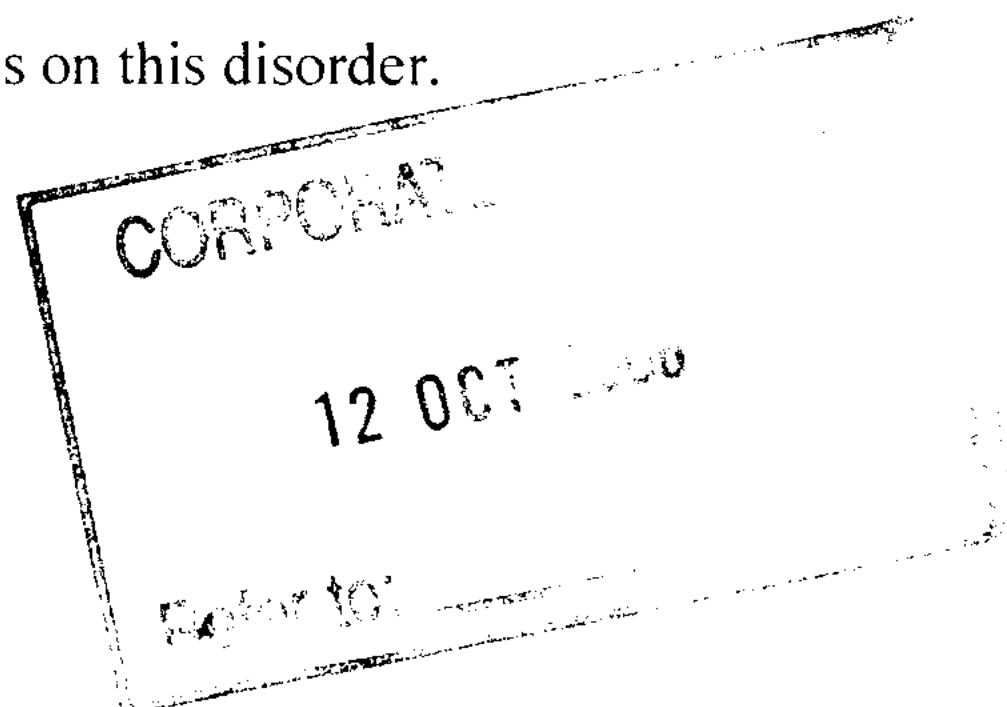
To: Each Local Authority.

At the October monthly meeting of South Tipperary County Council the following motion was adopted and it was agreed to circulate it to each Local Authority for support.

'That the Health Service Executive would identify in each region hospital beds for adults with an extremely rare metabolic condition called Maple Syrup Urine Disease. They have been attending the Children's University Hospital Temple Street since birth.'

I attach for your information explanatory details on this disorder.

Signed : 
John O'Mahoney
Meetings Administrator



I call on this council for help in providing hospital beds for patients over the age of eighteen with an extremely serious and rare metabolic condition called Maple Syrup Urine Disorder. These people have been treated in The Children's University Hospital Temple Street since they were born. As they are now over the age of eighteen beds are no longer available in this hospital. They continue to be monitored weekly through blood tests by the metabolic unit in Temple Street and every three months are required to have a check – up under the consultation of Dr. Monavari.

Maple Syrup Urine Disorder is a very rare metabolic condition. Treating a patient with MSUD as early in life as possible prevents mental retardation and death. Metabolic doctors and dietitians provide support, which aids them in helping to have a normal and as healthy life as possible. The same is required for adults. Even though they have grown up with this disorder they still need the support and monitoring from these people to help them through adulthood.

There are currently seven adults over the age of eighteen with this condition in Ireland. The Children's University Hospital Temple Street is the only hospital in the country that treats MSUD patients.

A blood test is sent once a week by Fast Track to Temple Street for Leucine analysis. The diet is adjusted according to results of blood test. If blood levels read 650 or higher, they re repeated sometimes on a daily basis until they reach the acceptable level of 200 – 400.

They have a very low immune system which results in them being more susceptible to infection. When they become unwell they can deteriorate very rapidly, for example; their walk, their speech and their concentration is greatly affected, and if neglected brain damage or death within a very short period can happen. They need immediate hospitalization with the proper treatment and facilities.

It is of the utmost importance that beds and staff that are qualified to deal with this condition are available at all times.