3 August 2012

The Hon. Katy Gallagher
Minister for Health ACT
GPO Box 1020,
Canberra, ACT 2601

Dear Ms Gallagher,

We are seeking your support of the inclusion of **CAH (Congenital Adrenal Hyperplasia)** to the **NSW/ACT Newborn Screening Register.**

Australia is one of the only developed nations in the world that does not screen for this condition. Newborn babies are starting their lives in intensive care wards unnecessarily because CAH is not included in current routine screening. The USA and New Zealand have been screening for CAH for more than 28 years.

Professor Garry Warne, recently retired from Melbourne's Royal Children Hospital described this as a "scandal" in comments on the MJA (Medical Journal Australia) Insight website. I have attached a copy of this article and an open letter to the Editor of the MJA for your information.

As the president of the Australian CAH Support Group, I feel compelled to write to you regarding this issue as my predecessors have done over the past 20 years. In the past two months we have nearly lost another little baby boy to CAH after he was discharged from hospital with undetected life threatening adrenal insufficiency.

In Australia 1 in 50 adults carry the CAH gene. 1 in 15,000 children in Australia will be born with CAH. ACT / NSW screening currently test for various conditions including Galactosemia which has a far lower incidence rate of 1 in 60,000.

Over the years around Australia, various committees and trials have been set up to prove the value of screening. It has been strongly recommended for inclusion on the NSW/ACT screening register by the NSW/ACT Newborn Screening trial committee and the Human Genetics Society of Australasia to the AHMAC of which you are a member. It would appear that the CAH screening recommendations seem to be continually overlooked. It is only a matter of time before we lose another baby to this life threatening condition if national screening is not implemented.

At an approximate cost of $2 per child for CAH newborn screening, a simple calculation would demonstrate that the cost of CAH screening would be more than offset by the reduced need for neonatal intensive care of CAH newborns ($50,000 per day). CAH screening would likely be a cost benefit to government. Another less quantifiable yet substantial benefit would be the reduction of undue emotional stress on families and less potential long term health consequences.

For your information I have attached the most recent personal story of a newborn baby with undetected CAH. Harrison suffered an adrenal crisis at two weeks of age and was admitted to John Hunter Hospital where he spent over a week in neonatal intensive care. I have also attached a recently published study and the letter Professor Garry Warne wrote to the MJA.

Ms Gallagher, I urge you to make a decision to include CAH in the current screening program.
We **cannot** afford to lose another child or subject another family to such easily preventable trauma.

Yours sincerely

Michelle Hoare
President, CAHSGA

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