



**Reflux Infants Support Association (RISA) Inc**

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Dear Ms McNeill,

The Reflux Infants Support Association (RISA) Inc has been concerned to hear that consideration is being given to confining the prescription of amino acid baby formulas (Neocate & Elecare) to paediatric gastro-enterologists exclusively.

This would be utterly disastrous to many families we support and represent.

Currently many of our members, managing babies and children with severe gastroesophageal reflux disease (GORD) are on extremely long waiting lists to see paediatric gastroenterologists. They are few and far between in Australia - and in some parts of the country, almost non-existent. As far as we are aware, there are very few in Western Australia for example. There are only two or three operating on a part time basis out of Princess Margaret in Perth and that's about it. The waiting list is over a year! For parents dealing with babies who are suffering extreme gastrointestinal issues, this is simply outrageous.

The idea that in the mean time a GP or paediatrician might not be able to prescribe Neocate or Elecare is simply outrageous. Tiny babies can't advocate for themselves. A baby left with an inflamed, nastily irritated gastrointestinal tract from cows milk & soy protein intolerance, unable to access an amino acid formula can suffer longer term consequences - no least ulceration of the oesophagus and intestine. The damage done to the jejunum of these babies can lead to significant atrophy of that part of the intestine and has been linked to the incidence of coeliac disease.

We would be concerned if this is being done for economic reasons. There appears to be a similar concern aimed at the increased prescription of proton-pump inhibitors in infancy as well. We firmly believe that the increased diagnosis of GORD & CMPI in infancy is not a consequence of over-zealous GPs - rather it is about relatively recent changes in the field of paediatric gastro-enterology and very slowly increasing awareness amongst parents that their inconsolable infants may actually be in pain. Essentially, advances in endoscopy, pharmacology and nutrition have allowed medical professionals worth their salt to rethink why babies cry. And that's leading to better outcomes for tiny babies who would otherwise be in awful, extended periods of pain.

Furthermore, reducing access to amino-acid formulas in the face of a rising allergy epidemic, in which Australia seems to be leading the world, would fly in the face of logic. You don't need us to roll out the statistics on that.

We would contend that not treating these babies properly and in a timely fashion is costing the health system a huge amount of money. We are aware of repeated presentations to emergency and admissions to hospital of children who are clearly in pain or rapidly losing weight remaining undiagnosed for ridiculously long periods of time. These are children who when finally diagnosed, respond rapidly to pharmacological treatment and/or change in diet. Further, the link between babies who exhibit the symptoms of severe GORD and the rate of diagnosis of post-natal depression in their parents has not been extensively documented but exists. RISA Inc does not consider it a co-incidence that the rate of infant GORD is almost identical to the rate of post-natal depression. If more were being done to educate parents and the medical profession about how to cope with a refluxing baby and when to seek help, a huge amount of money would be saved by the health system, and a lot of suffering alleviated for tiny babies and their distraught parents.

However, our main and current concern is to seek your assurance that Neocate and Elecare are will not be restricted to prescription by gastro-enterologists exclusively. We understand that this is an expensive item to subsidise. Perhaps there is a way of subsidising it by tin rather than by package of 8 tins in order to help mitigate the cost to the public purse. Most parents switching to Neocate or Elecare are already accustomed to buying formula for their child. This may be a more reasonable way to address the cost of the item in the PBS than reducing access to it.

Your early reply would be appreciated.

Joanne Matthews

**Advocacy Sub-Committee**

**Reflux Infants Support Association (RISA) Inc**

Cc Mr David Learmonth, Deputy Secretary

Ms Felicity McNeill, Assistant Secretary