



Reflux Infants Support Association (RISA) Inc

PO Box 1598

ARBN: 124 656 097

Fortitude Valley

ABN: 64 158 190 024

Queensland 4006

Ph: 07 3229 1090

Website: www.reflux.org.au **Email:** info@reflux.org.au

The Hon Dr Kim Hames MB BS JP MLA
Deputy Premier, Minister for Health, Minister for Tourism
28th Floor,
Governor Stirling Tower
197 St Georges Terrace,
PERTH WA 6000

Minister.Hames@dpc.wa.gov.au

Dear Minister,

I write on behalf of the Reflux Infants Support Association (RISA) to seek some guidance on behalf of our entirely volunteer management team as to a way forward for our organisation.

RISA Inc was formed in 1982 as the Vomiting Infants Support Association of Queensland, changing our name to RISA Inc in 2001. Though originally formed in Queensland, it now supports the parents of children suffering with Gastro Oesophageal Reflux Disease (GORD) Australia-wide. While the organisation operates nationally, many of our members are based in WA.

More and more doctors are coming to realise that the cause of significant infant distress is often GORD or allergic colitis due to cow or soy milk protein. While the prevalence of GORD in the general infant population runs somewhere between ten and 20 percent, the incidence among premature infants is significantly higher - often estimated at sixty percent or higher. Perhaps unsurprisingly, the incidence among the general infant population is not dissimilar to the incidence among the general adult population.

However, while the incidence rate is significant, awareness in the general population and among many medical professionals is significantly lacking. Even parents of children with severe and significant issues report frequent misdiagnosis and years without appropriate intervention.

Living with a child with significant reflux is extremely stressful for families. Children can develop dangerous symptoms that parents may fail to recognise and assume their child's ongoing distress is due to their own inability to settle the infant. Children with significant reflux can refuse to eat and drink, aspirate their food, suffer from sleep apnoea and cause long-term damage to the oesophagus from stomach acid burn. This is aside from the "laundry problem" of significant

vomiting (though this is not always a symptom). Children with significant reflux issues often suffer with significant sleep and feeding issues. While this is not the experience of all families of a refluxing child, those with severe issues are usually accompanied by a family under long-term stress.

Further, there is some anecdotal concern among reflux parents and some paediatric gastroenterologists that reflux babies are at a higher risk of harm from their parents given the extremely stressful situation their parents are put in, particularly because many reflux parents experience the same issues that are recognised as common triggers for shaken baby syndrome, a form of child abuse. There may also be a correlation between infants suffering from GORD and post-natal depression in mothers. Similarly, identified risk factors for post-natal depression are inevitably present in the families of children diagnosed with reflux. However, research in these areas is lacking.

RISA Inc volunteers provide support and advice to other parents of children and infants suffering from GORD through a phone and email service and also provides support through its online forums and web information. Where as well known sleep settling services of infants (like Tresillian or Karitane in NSW or community health centres in WA) are funded by state health agencies, RISA Inc receives no such government support. This strikes us a large gap in health care services significantly affecting a large proportion of Australian families. Further, parents of refluxing children are frequently given poor or erroneous advice from the existing services with members reporting being told that their inconsolably screaming child was suffering from "cot anxiety" or that it is normal for an infant to continually refuse to feed.

Given the prevalence of GORD in the infant population, the RISA Inc executive would like to be able to do more to both raise awareness amongst the medical and general population and provide a more sophisticated support service to suffering children and their families.

The RISA Inc executive would be interested in discussing these concerns or to be pointed in the direction of appropriate funding sources for this organisation.

Families of extremely unsettled infants would be grateful for an information campaign that allowed them to better understand the distress of their infants and provided them with the basic tools to be able to do something to assist them.

Families of refluxing babies are often met with "all babies cry" and "all babies vomit". But not all babies scream and vomit continually and many don't have the tools to know when their situation has become abnormal and they need to seek help. RISA Inc would like to work with government to improve this situation.

Not only do services for parents of reflux children need to improve, but information for parents and health professionals needs to improve. Given the

prevalence of GORD and its long-term effect on children's health as well as particularly maternal mental health, there is a strong argument for screening for this illness at both the 6 and 12 week community health check. Information needs to be provided in maternity wards and in particular Special Care and Neonatal wards where more premature babies and their families spend so much time.

There is much to do. We look forward to hearing from you.

Kinds regards,

Joanne Matthews