



3 MAY 2017

FOR IMMEDIATE RELEASE

INFANT REFLUX SEVERELY IMPACTS QUALITY OF LIFE

Parents are struggling to cope with the enormous difficulties of managing newborn babies with infant reflux, according to a new report from the Reflux Infant Support Association (RISA).

The report *Reflux rollercoaster: dismissal, delay and the cost to families and the health system* presents the results of a survey of 576 parents or carers of children diagnosed with gastro-oesophageal reflux disease (GORD).

The report found an alarming incidence of mental illness among parents of children experiencing GORD, with 33 per cent of respondents reporting postnatal anxiety or depression; three times the rate of the general population. The survey highlights the impact the serious illness has had on quality of life of many parents and families.

“The strain on parents is intense especially in the first year of life. Not only are these parents facing normal challenges of adapting to life with a newborn, but parents are seeking support for serious health concerns in their child including feeding issues, pain, and failure to gain adequate weight,” Mrs Joanne Matthews, President of the Reflux Infants Support Association, said.

Demonstrating the desperation felt by parents of children with GORD, despite the recommendations from SIDS and RISA, nearly 80% of survey respondents report their child is only able to sleep upright in a carrier, swing or in parent’s arms and resort to complementary therapies in more than 60% of cases.

The report shows that many parents experienced a lack of support by health professionals with 51 percent reporting that they felt health professionals did not adequately and appropriately support the care of their child.

The symptoms of GORD are not always clear and many parents are alarmed by the severity with 40 per cent of survey respondents visiting an emergency department with an extremely distressed child, and 67 percent of those parents returning to the emergency department two or more times with the same child.

The study also indicates the significant burden on the health system of delayed diagnosis and poor management of these children. There is extremely high usage of emergency, GP, specialist, pharmaceutical and allied health services among this population.

In addition, 36 percent of survey respondents reported financial strain with 33 percent reporting sustained absenteeism from their employment. More than half of all respondents also reported spending in excess of \$1000 in out of pocket health care costs.



Mrs Matthews says this survey is the tip of the iceberg and a lot more can be done to improve care for infants experiencing GORD and their families. The report outlines 10 recommendations to help families caring for an infant with GORD better access the services they need during this difficult time.

“What distinguishes a baby with GORD from other babies is usually the multitude and the severity of symptoms which many healthy babies will also experience at some time – including severe vomiting, inconsolable crying, irritability, poor sleep, frequent hiccups, eczema and a bloated stomach.

“We want to see improved access to information about GORD and its complications in hospitals, the child health record book, pharmacies, general practices and community health centres,” Mrs Matthews said.

“Furthermore, investment and commitment to new Australian research in the area is overdue.

“There needs to be research into the long term effect of GORD and its complications on infants and children, the effectiveness of treatment options, and the impact on parents, families and the health system.”

Mrs Matthews added, “However, we don’t have to wait to help families caring for children with reflux.

“RISA hopes to motivate friends, families and health care practitioners to reach out and support families caring for children experiencing GORD.

“If you know somebody caring for a child who may have GORD, check in with them. Encourage them to seek support. They really could be at the end of their tether.”

About Reflux Infant Support Association

RISA is a nonprofit charity that offers support to families of infants and children who suffer from gastro-oesophageal reflux and its complications. It is run by reflux families for the benefit of reflux families, and has done so since 1982.

For more information or to view the full report, visit our website at www.reflux.org.au/report

- Ends-

Media contact:

Joanne Matthews

RISA President

Phone: 0417673305



Email: joanne.matthews30@gmail.com

Interview and photo opportunities:

Joanne Matthews, RISA President

Joanne has been RISA President since 2011. She has two children with reflux; Charlotte (6) and Elizabeth (3). Charlotte was tube fed for two years due to the extent of her feeding aversion from reflux. She is happy to be interviewed about her experience caring for her children and navigating the health system.

Other reflux parents can also be made available for interview on request.

Joanne is speaking at the 2017 Patient Experience Symposium in Sydney, 3 May 2017