

Sunday, 31 March, 2019

Families and experts join forces to address the needs of children with complex feeding difficulties

For the first time, children who require feeding via tube, their carers and clinicians will come together in Sydney on Sunday, 31 March, as part of the ongoing Supporting Children with Complex Feeding Difficulties (SuCCEED) study.

The inaugural Tube Feeding Picnic 2019 will see over 100 people meet to share experiences about tube feeding their child, contributing to ground-breaking efforts to share knowledge and resources among tube feeding families throughout Australia.

Dr Chris Elliot, SuCCEED Chief Investigator and Staff Specialist Paediatrician, St George Hospital, said up to three quarters of children born prematurely, with developmental delay or chronic illness have difficulty being fed – but knowledge gaps make it difficult to quantify the impact of tube feeding.

“The most severely affected children cannot safely eat or drink enough to stay alive. For these families, every mealtime can be scary and stressful. Many parents tell us the process of feeding children at home via feeding tubes is both lonely and challenging,” Dr Elliot said.

Feeding difficulties arise from a diversity of health issues including preterm birth, cancer, cerebral palsy, autism, congenital heart disease and cleft palate, making it hard to measure the scope of tube feeding in the community and provide support.

“Although feeding difficulties are common – with studies estimating that up to half of parents with otherwise healthy children worry about their child’s feeding at some stage – little is known about the best ways to care for children who experience these difficulties.

“This is pioneering work – tackling the gaps in current services by using novel research methods to listen to families to identify and share best practices which will improve care,” Dr Elliot said.

SuCCEED is a unique partnership between researchers, clinicians and families. It is responsible for bringing together all nine multidisciplinary paediatric feeding clinics in NSW to better understand current practices – and also launched Australia’s first free, research-informed online resource dedicated to improving the experience of caring for children with complex feeding difficulties.

The website, www.childfeeding.org, provides guidance for the first four weeks of tube feeding a child at home – a time, Dr Elliot says, described as “the scariest and most difficult” by affected families.

“The website ensures access to clear information, 24/7, developed with guidance from families who are experienced in tube feeding their child.”

“Given the success of SuCCEED’s collaborative approach, we’re hopeful the Tube Feeding Picnic will be another step towards building stronger support networks between these incredible families, as well as with the clinical experts who’re passionate about creating better outcomes for these children,” Dr Elliot said.

Event details – Tube Feeding Picnic
Date: Sunday 31 March 2019
Location: Hill Pavilion, Sydney Olympic Park
Time: 10.00am – 2.00pm

SuCCEED is funded by Early Life Determinants of Health (ELDoH) – a clinical academic group under the Sydney Partnership for Health, Education, Research and Enterprise (SPHERE) – and South Eastern Sydney Local Health District (SESLHD).

Study partners include SESLHD, South Western Sydney Local Health District, Sydney Children’s Hospitals Network, University of New South Wales, University of Technology Sydney, Western Sydney University and Ingham Institute.

INTERVIEW OPPORTUNITIES:

- Dr Chris Elliot, SuCCEED Coordinator and Staff Specialist, Department of Paediatrics, St George Hospital
- Ms Khadeejah Moraby, Senior Speech Pathologist, Sydney Children’s Hospital Randwick, Project Officer SuCCEED Study
- Anna Ierardo, parent of child Emily

Contact Johanna Waide, Media Officer, SESLHD, to arrange interviews: 0417 017 149.

FACTS ABOUT TUBE FEEDING:

- International research found 40-70% of children born preterm experience some type of feeding problem(s) during childhood. This increases to up to 90% of children with significant developmental delay and chronic illness such as congenital heart disease, cleft palate and autism.
- Tube feeding is a way of providing nutrition, in the form of specialised formula, to a child’s body. It can help to provide the nourishment and essential nutrients a child needs to grow and develop when they are unable to eat enough.
- There are different types of tubes depending on a child’s needs. The two most common are NG tubes (inserted through the nose into the stomach) and PEG tubes (surgically inserted through the abdominal wall into the stomach).
- Most children start with an NG tube. Only some progress to a PEG if their feeding disorder is prolonged over months or years.
- NG tubes are taped to a child’s face and are easily pulled out. Some parents learn to re-insert tubes themselves at home. Others bring their child to hospital, potentially every day or every week for the duration of tube feeding.
- Families must learn to use medical equipment such as acid-base testing strips, pumps, syringes and to safely prepare medically prescribed formula.
- Tube feeding is not always permanent. Many children learn to feed on their own and have their NG or PEG tubes eventually removed.

