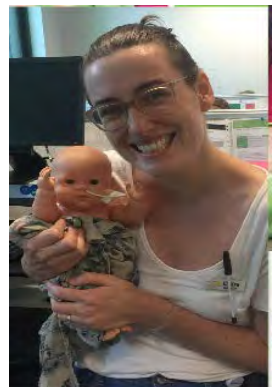


How a Consumer Advocate connected to innovate change

Queensland Children's Hospital (QCH)
Tube Feeding Project



Keren Pointon
& Claire Reilly



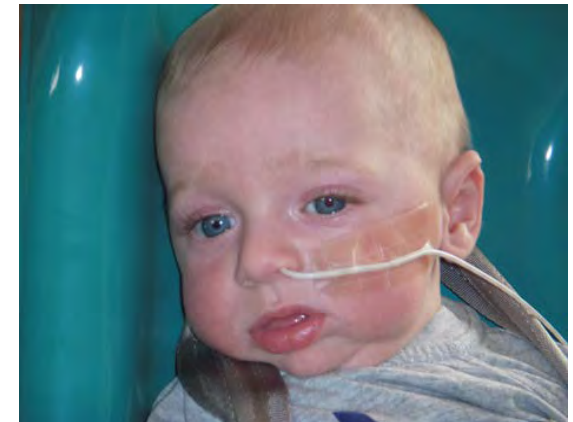
Presentation Outline

- What is Tube Feeding Dependency
- Keren's Story
- Claire's Story
- QCH Tube Feeding Project
- Lessons Learned
- Next Steps



Tube feeding dependency (TFD)

- TFD is an unintended consequence of temporary tube feeding
- Refusal to eat, drink, swallow
- TFD can affect quality of life of both the patient and the family
- TFD comes at a high personal and health system cost



Keren's Story - Tube Feeding Dependency



My first skin to skin contact with Ella – NG tube already in...



Ella learning to breastfeed in special care



Tube feeding 15 or more hours per day...

The dreaded feeding pump always there – an abnormal part of normal family life

Ella – Eating Again!

- Trust your instincts
- Research
- B.R.A.N. = **B**enefits, **R**isks, **A**lternatives, **N**o thank-you



Keren's Story – becoming a Health Consumer

Learning to Eat
Conference Jan
2011

Various Articles &
Grand Rounds Sep
2011

Suncorp Brighter
Futures Grants
2012 & 2015
\$10K

Joined CHQ Family
Advisory Council
2012

Half Marathon Fund
Raising 2013 to 2017
\$15K+

Joined HCQ
Collaborative with
QH 2017



Claire's Story

- Dietitian in the feeding clinic at Mater Children's Hospital
- Moved to QCH
- Hearing stories from families about tube feeding..
- Managing difficult patient tube weans
- Thinking there should be a better way...
- Met Keren!



QCH Tube Feeding Project: the reality of research..

Keren's fundraising for the QCH feeding team (~\$21,000) 2015



Produced a gap analysis report on temporary tube feeding + tube weaning 2016



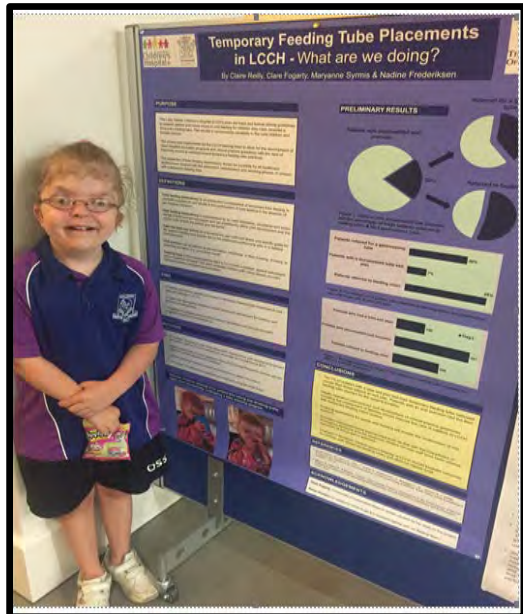
4 week student research on temporary tube feeding 2017



12 month student research project follow up study 2017-2018



Successful Woolworths Grant ~\$100,000 2018 - 2019



LETTER OF OFFER
Children's Hospital Foundation Grant Reference Number:
Grant Type: Woolworths Nutrition-Related Health Services R
Administering Institution: University of Queensland

I am delighted to make the following grant offer on behalf of the Foundation in support of your research:

Project Title: Implementation and evaluation of a feeding tube requiring temporary feeding tubes
Total Grant Amount: \$77,736 + \$20,000 Health Services Re GST)



Contents lists available at ScienceDirect

Journal of Pediatric Nursing



Characterisation of information Hospitals Provide Parents on Tube Feeding, Including Tube Weaning

Maryanne Symmis, BSpThy, Speech Pathologist – Advanced (Outpatients)*¹,
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Claire Reilly, B.Sc., MSc, APD, Dietitian¹

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How best to manage tube feeding?

Prevention & education to avoid tube feeding dependency

- ✓ Co-ordinated approach across all QCH
- ✓ **Create a tube exit plan**
- ✓ Include the family and support the family
- ✓ Clarify the reason & state the duration of tube feeding
- ✓ Clarify the feeding plan for tube and oral feeding *if appropriate*
- ✓ Document in medical notes
- ✓ Organise follow up
- ✓ Consider advice from the feeding team *if complex*

Lessons learned



**Change takes
time**

**Patience &
persistence**

**Fundraising
helps**

**Work together:
Clinicians &
Consumers**

**Co-ordinated
approach
across the
health service**

**Embed
sustainable
changes**

**Need
champions**

**Ask questions -
involve families
early on**

Next Steps

- Woolworths research grant completion
- State-wide rollout of education & prevention
- Research publications
- Churchill Fellowship application



Summary

- Tube feeding dependency can be an unintended consequence of temporary tube feeding
- Can be devastating for families
- High personal & health system cost
- There are better ways – process change & getting grants takes time
- Involving health consumers is a vital strategy for improving health outcomes



Thank you!

