

Sharing Our Experience In Using NGT And Gastrostomy Button For Feeding



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13th April 2013

INTRODUCTION OF THE RARE GEM : CHLOÉ

Chloe was born in Nov 2009.

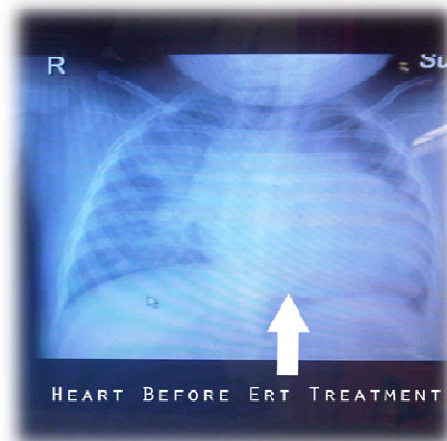
She was diagnosed with Pompe Disease in July 2010.

What is Pompe Disease?

Pompe disease is a rare inherited neuromuscular disorder that causes progressive muscle weakness in people of all ages.

Signs & Symptoms:

- ❑ “Floppy” baby (hypotonia). Difficulty sucking, swallowing, and/or general feeding because of weakened mouth, tongue, and facial muscles.
- ❑ A greatly enlarged heart (Cardiomegaly / Cardiomyopathy).
- ❑ Develop severe breathing difficulties and frequent lung infections.



OUR PROBLEM WITH FEEDING

Chloe had very poor weight gain.
At 7 months, she was only 5.7KG.

She has poor sucking and swallowing strength.

She experienced frequent vomiting after milk but it was common for infants like her to have GERD. Hence we decided to put her on NGT Feeding.



Pros of using NGT:

- ☐ Each feed took about 7-10mins to complete
- ☐ Chloe has good weight gain. At 18mths, her weight reached 10.5KG (50 percentile)
- ☐ Allows continuous feeding whenever she was unwell
- ☐ Easy venting of air from her stomach
- ☐ Ease of administering medication
- ☐ No restriction in her activities/movements
- ☐ No maintenance required

HOWEVER.....

We do not recommend NGT for long term feeding. Why?

NOV 2011

Cons of using NGT:

- ☐ Caused nose bleeds
- ☐ Higher risk of infections
- ☐ Difficulty in doing suctioning through the nose
- ☐ Caused higher air leakage from face mask
- ☐ More secretion and drooling
- ☐ Resulted in rashes on her face due to prolonged usage of hypafix. Needed to change position of hypafix daily
- ☐ Easily pulled out during play
- ☐ Various checks to be performed during every feed/NGT change
- ☐ Does not encourage spontaneous swallowing



SWITCHING TO PEG BUTTON

Buttons available in KKH at that time:

Bard by Bard Access Systems



Mic-Key by Kimberly Clark



We decided on Bard due to the following:

- ☐ Surgeon recommended it as a first button
- ☐ Homecare advised that it was better for healing around the stoma.
- ☐ It had a lower profile compared to Mic-Key.
- ☐ No need to check the water level of the balloon weekly
- ☐ No risk of puncture/leakage of the balloon
- ☐ Lower risk of button dropping out
- ☐ Durability

In July 2012, Chloe had her first gastrostomy button. The surgery was put on hold for 2 years due to her heart condition.

CONCERNS ON PEG BUTTON FEEDING

- ❑ Infections around the stoma
- ❑ Possible growth of granulation tissues around the button
- ❑ Leakage around the stoma, especially in sitting position
- ❑ Deflated balloon (for balloon type) will cause the button to fall out
- ❑ Back flow (when using Bard) if the anti reflux valve didn't close properly
- ❑ Preparation before bathing or swimming.
- ❑ Regular cleaning of the surrounding of the stoma and changing of gauze



WHY WE LIKE PEG BUTTON FEEDING

Chloe's face says it all!

- ☐ Improved facial appearance
- ☐ Ease of feeding
- ☐ No need for 'pre-feed' checks
- ☐ Better weight gain – 2KG in 3 months.
- ☐ Reduced secretion and drooling
- ☐ SPO2 reaches 99% (Max. 96% when on NGT)
- ☐ Possibility of offering blended diet
- ☐ Increased comfort



NOV 2012

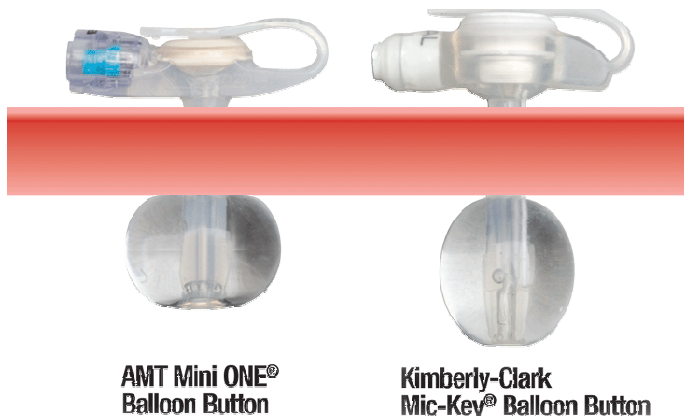
At 36 mths, she is 15.6kg and 104cm tall

Fundoplication was done
together with PEG
surgery to treat her GERD

SELECTING THE BEST PEG BUTTON

What we want to achieve:

- ☐ Minimal trauma during change
- ☐ Low profile
- ☐ Durability
- ☐ Low levels of back flow
- ☐ Reduced leakage around stoma
- ☐ No deflated balloon
- ☐ Low risk of button dropping out



New button at KKH :



