

THE WINSTON CHURCHILL MEMORIAL TRUST OF AUSTRALIA

Report by Rachel Hampshire  
2008 Churchill Fellow

The Peter Mitchell Churchill Fellowship to investigate the feeding assessment tools and therapeutic techniques used for medically compromised infants in neonatal intensive care units and feeding clinics - USA, Canada

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Signed:

Rachel Hampshire

Dated: 9/1/09

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## INTRODUCTION

The Peter Mitchell Churchill Fellowship to investigate the feeding interventions used with medically compromised infants in neonatal intensive care units and feeding clinics was conducted in the United States of America and Canada from the 20<sup>th</sup> of October through to 16<sup>th</sup> of December 2008. A summary of the key differences in practices are contained within this report.

I extend my utmost appreciation to the Churchill Trust, and in particular to my sponsor, the family of Peter Mitchell. It has been an honour indeed to be presented with such an invaluable opportunity.

The support provided by St George Hospital, Westmead Hospital, and my colleagues to allow the completion of this Peter Mitchell Churchill Fellowship has been much appreciated.

I would like to express my thanks to the many US and Canadian organisations visited that so willingly gave of their time to contribute to the project. Meeting with such dedicated individuals who presented with a wealth of innovative ideas and expertise certainly enriched my experience.

Finally, I wish to thank my husband Trent who is my rock of support. You enabled me to dream, to pursue and to fulfill.

## EXECUTIVE SUMMARY

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The Peter Mitchell Churchill Fellowship to investigate the feeding assessment tools and therapeutic techniques used with medically compromised infants in neonatal intensive care units and feeding clinics was conducted in the United States of America and Canada from the 20<sup>th</sup> of October through to 16<sup>th</sup> of December 2008. The aim of the project was to explore differences in paediatric feeding practices and the application of various approaches to the Australian population that would enable more efficacious intervention and lead to improved outcomes for children.

### Highlights

- Attending 5 days of seminars by Dr Catherine Shaker, Paediatric Resources Inc. on Paediatric Feeding and Swallowing and Paediatric Swallowing Studies at Tri-City Medical Centre, Oceanside, California, USA
- Attending the internationally acclaimed course by Dr Kay Toomey on "Picky eaters versus problem feeders: The SOS approach to feeding" in Connecticut, USA
- Meeting with therapists publishing in the area of paediatric feeding and observation in the Neonatal Intensive Care Unit at Hospital for Sick Children, Toronto, Canada
- Visiting with Ms. Allison MacDonald, Speech Language Pathologist at Alberta Children's Hospital, Canada regarding the Fiberoptic Endoscopic Evaluation of Swallowing (FEES) clinic

### Conclusions

Variability in paediatric feeding practices exists within and between countries, states, cities, hospitals, and clinicians. However, a number of aspects of feeding intervention observed abroad should be considered to enable better service provision and enhance clinical outcomes here in Australia.

### Implementation and dissemination

- Information obtained will be presented across NSW area health services and articles submitted to allied health publications
- Therapists will be individually trained in the use of evidence-based feeding assessment and therapy techniques and implemented on a daily basis.
- Principles learned will influence policy development in relation to feeding in the Neonatal Intensive Care Unit
- The potential for implementing alternative service delivery models for paediatric feeding will be scoped
- Research and relevant pilot projects focusing on effectiveness of specific feeding interventions and the use of various alternative service delivery models will be facilitated

## PROGRAMME

Location	Institution	Study
Oceanside, California, USA	Paediatric resources Inc. Tri-City Medical Centre Dr Catherine Shaker	Paediatric Swallowing and Feeding (October 22-23) Paediatric Swallowing Studies (October 24) NICU Swallowing and Feeding (October 25-26)
Washington DC, USA	Children's National Medical Centre	Paediatric feeding in the acute inpatient setting
Baltimore, USA	Kennedy Krieger Institute	Models of residential intensive therapy
New York, USA	Morgan Stanley Children's Hospital of New York - Presbyterian	Paediatric feeding in the acute inpatient setting
Paterson, New Jersey, USA	St Joseph's Medical Centre	Models of intensive therapy
Hamden, Connecticut, USA	Education Resources Dr Kay Toomey	Picky eaters versus problem feeders: The SOS approach to feeding (November 7-9)
Toronto, Canada	The Hospital for Sick Children	Cleft Palate Clinic model Projects and publications
Calgary, Canada	Alberta Children's Hospital	Paediatric Fiberoptic Endoscopic Evaluation of Swallowing Clinic Multidisciplinary management of feeding
Vancouver, Canada	British Columbia Children's Hospital	Multidisciplinary management of feeding
San Francisco, California, USA	NOMAS® international Ms M.M. Palmer Kaiser Permanente Medical Center	NOMAS® certification course (December 4-6)
Los Angeles, California	Children's Hospital Los Angeles	Paediatric feeding in the acute inpatient setting Cleft palate clinic model

## AIM

The purpose of the project was to look for evidence-based, new and innovative ideas in feeding practices for infants and children that could be readily applied to the Australian population to enable more efficacious practices and improve feeding outcomes.

Specifically, the aims of the project were to:

- Investigate feeding assessment tools and therapeutic techniques used in Neonatal Intensive Care Units and feeding clinics for clinical and research purposes
- Examine and compare service delivery models such as:
  - Admissions for intensive feeding therapy
  - Multidisciplinary feeding clinics
  - Group therapy

## BACKGROUND

Paediatric feeding difficulties are common, affecting between 3-10% of all children (Chatoor, 2002; Lindberg, Bohlin, & Hagekull, 1991). The role of the Speech Pathologist is to assess and treat infants and children who experience difficulties with eating and drinking. For example, this may include assisting premature infants transition from tube to sucking feeds, babies with cleft palate to feed more efficiently, or children feed safely when they present with swallowing difficulties. This usually requires consultation with other health professionals involved in care to ensure a holistic approach.

Assessment and management of paediatric feeding difficulties by a Speech Pathologist is usually comprised of examining and modifying:

- Mealtime environment
- Daily mealtime routine
- Positioning
- Food types, textures, flavours, temperature, appearance, and quantities
- Equipment (e.g. spoons, bowls, teats)
- Facilitation techniques by the therapist or caregiver
- Oral motor therapy

Feeding difficulties may have significant implications for the child and their family. A child's medical status may be compromised by poor nutrition and suboptimal growth which in turn may affect developmental outcomes. The quality of life and emotional welfare for the child and their family may be reduced. Studies have shown increased stress and anxiety for caregivers of children with feeding difficulties; there may be profound effects on self-esteem, self-efficacy and confidence in parenting (Craig, Scambler, and Spitz, 2003; Crist, McDonald, Beck, Gillespie, Barrett & Matthews, 1994). In clinical practice, parents have often expressed feelings of inadequacy and

disempowerment from not being able to feed their own child. When mealtimes are particularly difficult for a family, social isolation has been observed as they withdraw from social outings which often involve eating and drinking. Furthermore, if a child experiences feeding difficulties, it is possible that speech issues may ensue given early feeding skills may be precursors to later speech sound development (Morris & Klein, 2000).

Therefore, there is a responsibility to be aware of and adopt more efficacious feeding practices used elsewhere to continue to provide a high level of clinical training to Speech Pathologists in this specialised area of practice which reflect recent advances in the field. This will ensure benefits to the patient and their family by improving quality of care using an evidence-based approach. With treatment being more efficient, length of admissions and episodes of care may be reduced. This is likely to result in less financial burden for hospitals.

### FEEDING INTERVENTION: DIFFERENCE OVER DISTANCE

It is well established that there is variability in paediatric feeding practices particularly in Neonatal Intensive Care Units (Lee, Ohlsson, Synnes, Sale, 2000; Blackwell, Eichenwald, McAlmon, Petit, Linton, McCormick, Richardson, 2005; Eichenwald, Blackwell, Lloyd, Tran, Wilker, Richardson, 2001). Therefore, it was expected that during the course of the fellowship that differences in approaches to feeding intervention would be observed. Differences were observed within and between:

- Therapists
- Hospitals
- Cities
- States
- Countries

It is assumed that variability in feeding practices observed is present due to a number of factors including the nature of the health systems, demographics, culture and resources of the organisation, and the level of education and training of the therapist in this specialised area. While understanding the cause of this variability was not within the scope of this project, it certainly should be considered in the interpretation of the results and requires further research.

The report hereon documents a few of the key differences in practice that were observed. It is not intended to be an exhaustive list, but to provoke thought of ways to potentially improve quality of care. It is envisaged that individual clinicians should approach the following with a view to appraise each method.

## METHODS OF ASSESSMENT

### **Fibreoptic Endoscopic Evaluation of Swallowing (FEES)**

One recognised method of evaluating swallowing function is via FEES. It was first described by Langmore, Schatz, & Olsen in 1988 and is usually conducted by an Ear Nose and Throat Specialist and Speech Pathologist. It involves the trans-nasal insertion of a flexible fibreoptic endoscope to enable assessment of laryngopharyngeal movements during respiration and swallowing, and the management of saliva.

The advantages of FEES as documented by Morris & Klein (2000) include:

- No radiation exposure as compared with other methods of assessment such as Modified Barium Swallow Studies (discussed below). This is an important consideration, particularly in light of assessing chronically ill infants and children who have had regular radiation exposure and/or require frequent swallow studies.
- Real food and liquids are used without the need for contrast materials
- The equipment is portable, so the study can be performed in a more familiar environment for the child. It also allows the child to be positioned in his/her own chair or on the caregivers lap
- It gives information about nasal, pharyngeal, and laryngeal structures before or after swallowing

It should be noted that this procedure is invasive and may be uncomfortable for the infant or child. It is also limited to observations before and after the swallow, and does not allow visualisation of the actual swallow (Morris & Klein, 2000). The therapist needs to consider carefully whether FEES is the most appropriate procedure, bearing in mind the child's compliance, nature of their disorder and perceived benefits.

While this technique is known to be used with the adult population in Australia, it is not used frequently with the paediatric population. Likewise, few centres visited in USA were using FEES with infants and children. However, at Alberta Children's Hospital in Canada, FEES are being conducted routinely. I had the pleasure of meeting with Ms Allison MacDonald who has extensive experience in conducting FEES with Ear Nose and Throat Specialists. Ms MacDonald provided me with education regarding considerations and resources required for establishing such a clinic, observation and clinical discussion of FEES studies with a tour of facilities. As an outcome of the visit, networks were established should resources for a paediatric FEES clinic be obtained in Sydney.

### **Modified Barium Swallow studies (MBS)**

Another test used to analyse swallowing function is a Modified Barium Swallow (MBS). This procedure involves ingestion of food and fluid contrasted with barium whilst in a fluoroscopy suite and the study is videotaped. It is usually performed by a Radiologist in conjunction with a Speech Pathologist.

Modified Barium Swallow studies are used with the paediatric population throughout Australia. Similarly, MBS was the swallowing assessment procedure most commonly used in hospitals visited in the USA and Canada other than bedside/clinical examinations. The following variations in practice were noted between centres:

- There was huge range in how frequently MBS procedures were ordered. This appeared to be regardless of the size of the hospitals. While some clinicians/hospital staff ordered MBS studies routinely (e.g. multiple per week), others used this procedure more sparingly.
- While some clinicians prescribed thickened fluids for infants in Neonatal Intensive Care Units prior to an MBS procedure to assist with swallow coordination, other therapists chose to keep infants nil by mouth until thickened fluids were firstly tried during the MBS.
- Viscosity of fluids tried during the study were able to be standardised by some hospitals by the purchase of pre-packaged barium in pudding, honey and nectar consistencies. However a consistent issue arising regardless of method used for adding the contrast agent was being able to accurately compare the viscosity of the fluids tried with the barium added, versus without barium due to its properties. In clinical practice, this makes it difficult to accurately provide recipes prescribing the amount of thickener to be added to fluids at home to replicate the consistency deemed safe during the MBS procedure to ensure the infant or child is not placed at risk of aspiration.
- Most hospitals tended to limit screening time to  $\leq 2$  minutes for neonates and  $\leq 5$  minutes in older children while occasional exceptions were noted.
- A variety of specialised feeding chairs used during swallow studies were observed. Some were specifically designed by the hospitals' engineering department (refer to picture below), others are commercially available. These included the Multiple Application Multiple Articulation (MAMA) seating system, Tumble Form adaptive positioning seat, and Hausted All Purpose chair.



Custom built chair for Modified Barium Swallow Procedures created by:  
British Columbia Children's Hospital, Vancouver, Canada

## **NOMAS® certification**

The Neonatal Oral-Motor Assessment Scale is considered to be a reliable tool for evaluating neonatal sucking patterns in preterm and term infants (Palmer, Crawley & Blanco, 1993). It is used to describe infant feeding patterns up to approximately 8 weeks post-term. It is a non-invasive visual observation method where non-nutritive sucking and nutritive sucking of infants during the first 2 minutes of a regular feeding are scored. The examiner is then able to classify the sucking pattern as normal, disorganized, or dysfunctional. Accurate categorisation of sucking performance is considered essential to ensure appropriate treatment recommendations for infants.

The NOMAS® certification course was presented by M.M Palmer at Kaiser Permanente Medical Center in San Francisco over 3 days. The training included bedside observation and scoring sucking patterns of infants during feeding in the Neonatal Intensive Care Unit. To be considered certified in the NOMAS®, a reliability examination is taken requiring the participant to observe and score 5 infants' sucking patterns. It is expected that the participant achieve 100% accuracy in classification of each of the infants' sucking patterns, and 85% agreement on 28 scoring items per case.

I was particularly interested in its application to research. NOMAS® international advertises that this assessment enables the examiner to take pre and post test measures of neonatal sucking patterns to evaluate the effectiveness of intervention program and to document developmental progression and changes in oromotor patterns. In my endeavor to introduce more efficacious feeding practices across the hospitals in which I work, the NOMAS® may be used as one of the components to evaluate the feeding intervention programs implemented with neonates.

## **FEEDING EQUIPMENT IN THE NICU**

An integral part of feeding intervention is selecting the most appropriate feeding equipment to ensure safe and efficient feeding for the infant. Both in Canada and the United States, variations in the type of feeding equipment commercially available were apparent, as well as clinician's preference. The common feeding apparatus found in Neonatal Intensive Care Units and Children's Hospitals are found below.

- Dummies (pacifiers)
  - Gumdrop™ pacifier
  - Gumdrop™ preemie pacifier
  - Soothie® pacifier
  - Wee Soothie® preemie pacifier
  
- Teats (nipples)
  - Enfamil® standard-flow soft nipple
  - Enfamil® slow-flow soft nipple

- Similac® infant nipple
- Similac® premature nipple

Due to infection control procedures, the teats listed above were all single use, disposables.

- Specialised feeding systems
  - Bionix® controlled flow baby feeder
  - Medela SpecialNeeds feeder® (formerly Haberman feeder)
  - Mead Johnson cleft palate feeders
  - Pigeon cleft palate teat and squeeze bottle
  
- Thickening agents used with fluids
  - Rice cereal
  - Simplythick® honey consistency (xanthan gum based)
  - Simplythick® nectar consistency (xanthan gum based)

### **NTrainer System™**

Premature infants in the Neonatal Intensive Care Unit often have disorganised oral skills and many unable to suck or feed orally (Bu'Lock, Woolridge & Baum, 1990), hence discharge from hospital can be delayed. The recent development of the NTrainer has become the topic of much discussion for therapists working in neonatal feeding. The NTrainer is a biomedical device where an electronic pacifier is used to examine and facilitate neonatal sucking behaviours. Poore, Zimmerman, Barlow, Wang & Gu (2008) describe that The NTrainer is wheeled beside the infants crib in the Neonatal Intensive Care Unit, and 3 minutes of stimulation provided during tube feeds up to 4 times per day until the infant had established oral feeding. A pulse is delivered to modify the pressure and shape of the infants preferred Soothie® pacifier according to the temporal features of a non-nutritive suck. The authors concluded that the NTrainer has been shown to accelerate non-nutritive suck development and oral feeding success in preterm infants who are at risk of oromotor dysfunction. While further research is needed, this innovative device is another consideration for enhancing the efficacy of feeding therapy within the Neonatal Intensive Care Unit.

## **MULTIDISCIPLINARY APPROACH TO FEEDING**

One of the challenges with feeding clinics in Australia is having access to a comprehensive multidisciplinary team to enable holistic feeding assessments. Most therapists and hospitals recognise the importance of multidisciplinary teams, but due to limited resources, time constraints and logistics, it is often difficult to achieve. It should be noted that more often than not, feeding clinics in Australia do involve two or more disciplines seeing the patient either as a team or individually. However, achieving representation from upward of six disciplines in a feeding clinic where the team jointly see the patients is rare.

A number of multidisciplinary feeding clinics were observed throughout the course of this Churchill Fellowship. The following features were noted:

- Representation from a number of professions with delineation of roles. Teams visited typically included:
  - Speech Language Pathologist
  - Occupational Therapist
  - Physiotherapist
  - Paediatrician
  - Dietitian
  - Paediatric Gastroenterologist
  - Psychologist or Social Worker
  - Nurse practitioner
- Coordinated approach to care enhancing efficiency of service provision and effectiveness of communication between team members
- Streamlining of administration with intake, case history taking, documentation and reporting. A number of administrative protocols and forms were obtained from clinics visited to provide a basis from which similar systems can be established in the workplace.
- Custom built facilities conducive to multi disciplinary feeding clinic. Alberta Children's Hospital's clinic room can be seen below (Calgary, Canada). The sessions took place in a room with a kitchen complete with food, fridge, microwave, stove, armchair for breastfeeding and highchair for example. This was to promote a naturalistic environment in which to observe the child eat and for ease of food preparation. It was fitted with a one way mirror which the team sat behind to watch the feeding session and discuss observations. The mealtime was also videotaped which allowed data collection to assist with analysis of behaviours and oromotor skills as well as to document progress. The videotapes were also used as a tool to provide parent feedback and education.



Feeding Clinic, Alberta Children's Hospital (Calgary, Canada)

### **Models of Intensive Feeding Therapy**

Facilitating change in a child's oromotor skills and feeding ability, particularly transitioning a child from enteral (tube) feeds to oral feeds can often be an ongoing clinical challenge. While most feeding difficulties resolve within the first few years of life, around 3% of cases may become a chronic issue (Kerwin, 1999). However, some support for intensive interdisciplinary feeding programs is emerging (Greer, Gulotta, Masler & Laud, 2007; Kerwin, 1999). I was able to attend two organisations, Kennedy Krieger Institute, Baltimore, USA and The Center for Pediatric Feeding and Swallowing at St Joseph's Children's Hospital, Patterson, New Jersey which both offered intensive interdisciplinary feeding therapy. The child would first be assessed by the multidisciplinary team. The multidisciplinary teams typically included a behavioural analyst, paediatrician, occupational therapist, speech pathologist, physiotherapist, and nurse practitioner. The team then decides on the treatment model required, and the patient would be admitted to or attend on a daily basis purpose-built residential facilities to receive an individualised feeding program. This may include daily therapy with the physiotherapist, speech pathologist and occupational therapist aimed at improving subskills required for efficient and effective feeding. The child's weight, growth and health is monitored by the nurse and/or paediatrician. In addition, the child participates in several feeding sessions each day. Data collection was imperative during mealtimes and analysed by the behavioural psychologists to measure change.

### **SOS Approach to Feeding**

The distinction between the behavioural approaches to the management of feeding difficulties was evident when visiting the various paediatric feeding programs. I had the opportunity to attend a 3 day seminar on the internationally acclaimed "Sequential Oral Sensory approach to feeding program" by Dr Kay Toomey in Connecticut, USA. This is a multidisciplinary approach to feeding intervention that considers sensory, motor, behavioural, oral, medical and nutritional factors in order to holistically evaluate and treat feeding and growth issues in children. What was appreciated most about this approach is that it founded on the developmental stages and skills that are noted in typically developing children, and these are worked towards in a step-by-step hierarchy of skills and behaviours required to successfully transition toward oral feeding (Toomey, 2007). It uses positive reinforcement with normal social reinforcement opposed to tangible, object based reinforcement. The SOS approach to feeding uses systematic desensitisation in treatment rather than flooding in order to help normalise the child's attitude to feeding.

This program can be implemented in a variety of settings. It was unique in that the approach was shown to be effective in group therapy with carefully selected groups. Group selection was based on developmental age, skill level, presence of allergies, and goals (Toomey, 2007).

The SOS approach to feeding can be used with a wide clinical population including children between 1-9 years of age presenting with autism spectrum disorder, medical disorders, sensory, oral motor and/or motor disorders, mild-moderate neurological

conditions and fussy eaters (Toomey, 2007). For these reasons, it is anticipated that the program can immediately be applied to my current clinical practice.

## CONCLUSION

This Peter Mitchell Churchill Fellowship has enabled the comparison of paediatric feeding practices across Canada and the United States of America to those used here in Australia. While there is variability within and between countries, states, cities, hospitals, and clinicians, it was apparent that a number of practices should be considered to better service provision and improve clinical outcomes.

## RECOMMENDATIONS

In the context of my current role across the eastern and central clusters of Sydney West Area Health Service and the central network of South Eastern Sydney and Illawarra Health Service, I will be:

- Disseminating information through presentations across NSW area health services and existing paediatric feeding networks meetings
- Submitting articles to allied health publications
- Individually training therapists in the use of new evidence-based feeding assessment and therapy techniques and implementing them on a daily basis in my own clinical practice
- Influencing policy development in relation to feeding in the Neonatal Intensive Care Unit
- Scoping the potential for implementing alternative service delivery models for paediatric feeding, in particular:
  - sourcing funding for a broader multidisciplinary team
  - investigating the use of group feeding therapy
- Investigating the feasibility of developing a Fiberoptic Endoscopic Evaluation of Swallowing (FEES) Clinic in Sydney
- Facilitating research and relevant pilot projects focusing on effectiveness of specific feeding interventions and the use of various alternative service delivery models

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