

Churchill Fellowship Report 2013



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Clinical Nurse Consultant and Churchill Fellow 2013

The Bob and June Prickett Churchill Fellowship to explore international services and practical management strategies to improve inpatient hospital experiences for children and their families with stomas, complex wounds and pressure injuries.
USA- Cincinnati, UK- London, Sweden- Goteborg. May 2014- June 2014.

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Dated

Dianne Greathead

12/08/14

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Introduction

While paediatric nursing can be one of the most rewarding experiences, like all nursing cohorts it can also be faced with some challenging opportunities. The simple goal of improving the hospital experience for a child and their family can be met with a complex grid of limitations and obstructions.

Early surgical interventions reducing ongoing hospital admissions for the child with a complex diagnosis can have a marked effect on the quality of life, for not only the child, but also the family. Returning children to their home environment safely is the optimum goal; this however is sometimes delayed until staged wound healing has been achieved along with education and support not only with the primary carer but also within the community. Improving both clinical nursing practices and education frameworks engaging innovative evidence based pathways extending from the inpatient to the outpatient will optimise the overall wellbeing of the child. This in turn will improve the confidence of the family to continue to care for the child in the home environment with a supported network of health professionals.

Being alert for the ongoing complications related to extended length of stay and decreased mobility can reduce the risk of developing hospital-acquired complications such as pressure injuries. While such injuries are uncommon in the paediatric environment when they do occur they can have devastating effects. To address these risks, exposure to hospitals that are world renown for risk identification and preventative intervention has also been achieved.

Many people both directly and indirectly have assisted me in my research. Exceptional support from peers has enabled me to experience as much as possible during this time. Challenging situations have not gone unnoticed and respect for those being cared for has always been demonstrated at the highest level. The assistance with the coordination of my experiences while travelling has been wonderful and has allowed me to enjoy my learning in a safe and welcoming environment wherever that has been.

I believe strongly in the pursuit of excellence in nursing the children in our care and the WCMT has allowed me the opportunity to travel to Cincinnati Children's Hospital, Great Ormond Street Hospital, Chelsea and Westminster Hospital and Kings College Hospital, following these visits I concluded my fellowship at the World Council Enterostomal Therapist Conference in Sweden. During all this time I was able to observe first hand the access to, and implementation of, resources, clinical skill and work practices that are available to families and children around the world. Meeting with motivated paediatric nurses through out the world has extended my knowledge network and linked me into professional resources with a common goal. From these meetings and experiences I believe I am able to integrate a sound inclusive service profile for the children in our care both within our hospital and within the communities they reside.

Acknowledgements

I wish to sincerely thank the Winston Churchill Memorial Trust of Australia for the opportunity to travel and be exposed to some of the most interesting and dynamic people, places, and situations. The opportunity to indulge my passion for paediatric nursing and extend my knowledge and international connections has been both energizing and humbling at the same time. At every step of the way, from the application process to the wonderful correspondence during preparation for my trip and on my return, I have been supported and guided confidently and professionally with a very personal touch.

I would also like to acknowledge and thank one of the most generous and interesting men I have had the pleasure of meeting since I have engaged on this life changing experience. Mr. Bob Prickett and his late wife June have been personally sponsoring Churchill Fellows for many years and their vision, commitment and generosity have seen more than 32 fellows travel around the world to guide and influence improvements in the health of Australians. I am very proud to be the recipient of the 2013 Bob and June Prickett Fellowship award.

My referees, Professor Peter Borzi and Professor Roy Kimble have ensured the challenges they give me have only added to my quest to provide the best nursing care to children in my path. Their

exceptional expertise and internationally acknowledged skill has stood me in good stead on my journey. I also wish to thank my nursing director, Karyn Ehren, Churchill mentor Anita Inwood, members of the Medical and Nursing Executive team at the RCH and the CHQ Board for their support for all staff pursuing excellence in their chosen field.

To the amazing staff I have met along the way, Julie Rogers and her wonderful team (USA) and the delightfully spirited Helen Johnson and her fabulous team (UK), Niamh Geoghan (UK) for her resources and inclusion and Kumal Rajpaul (UK) for his passion, insight and patience. Thank you for your energy and your commitment.

Finally I wish to acknowledge my family, their love and belief, support and encouragement has been unending.

Executive Summary

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Project Description:

- To explore international services and practical management strategies to improve inpatient hospital experiences for children and their families, with stomas, complex wounds and pressure injuries. Cincinnati Children's Hospital USA. Great Ormond Street Hospital UK. Kings Hospital UK. Chelsea and Westminster Hospital UK. WCET Sweden.

Highlights:

- Meeting with multiple nursing teams at Cincinnati Children's Hospital, Great Ormond Street Hospital, Chelsea and Westminster Hospital and King's College Hospital including Paediatric Urology, Stoma and Complex wound care, Spina Bifida team, Gastro intestinal rehabilitation and transplant outpatient clinic team, Patient safety team, Gastro- Colorectal ward and Tissue viability rounding.
- Attending surgery with staff Consultant.
- Meeting and spending time with Tissue Viability Nurse Consultant at Kings College Hospital, leader in field of nursing with wound care and treatment. Being informed of education packages and nurse desktop learning points.
- Alerted to resources for children with Ostomy surgical procedures. Spending time with Stomal Therapist and educated on altered procedures and success rates of such.
- Attend the World Council of Enterostomal Therapist international meeting in Sweden.
- (Social Highlights) Attending a Reds Baseball game, a school Prom, (USA) The Royal Marines Marching Retreat (UK), the Churchill war rooms London.

Recommendations:

- Routine inclusion of psychological support for pre-teen and teenage children prior to undergoing body disfiguring surgery improves the coping strategies engaged by this group of children and in some cases reduces hospital length of stay.
- Development of paediatric applications for medical history and appointments to assist with ownership of data, making appointments and sharing personal information.
- Accessible and dynamic staff and patient training modules which are timely and current improve the buy-in from ward nursing staff to confidently educate routinely and opportunistically both children and their family.
- Parent and carer information and instructional alerts when children enter an area of the hospital that is classified as Red Alert for potential injury. Traffic light system modified.
- The Clinical Nurse is instrumental in preparing information for discharge via a standardised check list as soon as the admission interview is complete. Pre-arranged discharge times to ensure adequate flow of patients through hospital and streamline return to the home environment.
- Clinical Nurse completes initial patient summary and questionnaire at outpatient clinic visit and to run device change clinics to reduce wait times. GE assessment details to be forwarded to treating team for review.
- Nurse led transition modules to both adult services and community/ home/ local/ school environment ensure consistent information, support and care for all children.
- Inclusion of family members to positively engage in their continued responsibilities of care while the child is in hospital, empowering them through information and education on how they may do this. Frequent formal rounding sessions are held with both inpatient staff and out patient staff (in some cases weekly and in other cases daily) to ensure information sharing and patient expectation is consistent and planned.
- The use of Clinical Pathways for standard procedures.
- External electronic access to information regarding the hospital, staff, procedural preparation and general length of stay to allow parents and carers to access this when required without restriction.

Dissemination:

- Publication of this report on the WCMT website 2014.
- Summary report presentation to the Children's Health Queensland Board.
- Summary report presentation to the AWMA.
- Summary report of paediatric pressure injury prevention and intervention to the Queensland Pressure Injury Prevention Strategic Advisory Panel.
- Summary report to AASTN and journal publications
- In-house education sessions based on recommendations and findings to be conducted once these have been endorsed and implemented.

PROGRAMME

DATE	ORGANISATION	CONTACT PERSON
8 th May – 16 th May 2014	Cincinnati Children's Hospital <ul style="list-style-type: none"> • Irritable Bowel Disease Clinic, Gastroenterology Clinic, • Spina Bifida Clinic, • Urology Inpatients and outpatient clinic • Tissue Viability Inpatient Nursing Service • Patient and family safety and rounding 	Julie Rodgers , International Liaison, Nursing. Jeanne Harjo , Intestinal Rehab and transplant clinic BJ Manz , Paediatric Urology, Spina Bifida Dr. Van der Brink , Urologist Anne Blevins , Stomal therapist and Tissue Viability Nurse Nan Tobias, Katie Mueller , Paediatric Urology Dr Sam Kocoshis , Gastroenterologist Dawn Hall , Patient Safety Wendy Ungard , Gastro-Colorectal Ward NP
22 nd May – 10 th June 2014	Great Ormond Street Hospital, London. UK	Helen Johnson , Stomal Therapist Jan Martin , Wound and Skin Integrity Nurse
6 th June and 9 th June 2014	Chelsea and Westminster Children's Hospital	Niamh Geoghegan , Urology Nurse Specialist and Stomal Therapist.
9 th June 2014	Kings College Hospital	Kumal Rajpaul Denmark Hill London, SE5 9RS
11 th June – 13 th June	Ostomy company visit and Tour	Anita and Paula Salts Australia
14 th June – 19 th June 2014	World Council of Enterostomal Therapists (WCET) 20th Biennial Congress Sweden	Contact: Eva Carlsson , Convenor Swedish Exhibition and Congress Centre Gothenburg Sweden.

BACKGROUND

As I write this report Brisbane is on the cusp of transitioning the two Queensland Paediatric hospitals, The Royal Children's Hospital (RCH) and the Mater Children's Hospital (MCH) onto one site. By the end of 2014 the Lady Cilento Children's Hospital (LCCH) will open the doors to the public and support the health of every child in the state and indirectly further afield. The opportunity exists to influence and lead the service profile of General Surgical nursing and Stomal Therapy Nursing through this transitional phase and beyond and to continue to implement the evolving delivery of world-class care to the children and families of Queensland.

Pressure injuries in children are considered rare however exact statistics and data world wide is incomplete. Due to the historical association of pressure injuries and bedsores with the elderly bedridden patient, the collation of paediatric data, prevention and management is still evolving. One fact that has been highlighted is that indeed although these injuries are less frequent in the paediatric population than in the adult population, they do occur and they can have devastating results. In some instances these injuries can be the cause of disfiguring surgery and very infrequently, amputations. Australia sits with the rest of the world with reports clearly identifying the number of pressure injuries developing in the paediatric intensive care setting is considerably greater than the number of pressure injuries in non-intensive care settings. Again accurate data relating to this is sporadic and incomplete. Gathering and collating this data will directly influence the treatment options for all children in our care. Cincinnati Children's Hospital has taken action and been instrumental in developing a Quality Improvement (QI) bundle of solutions.

The challenge to educate both parents and care givers, while risk is assessed and strategies are implemented, continue. The role for a specialized Clinical nurse to educate and plan intervention strategies while collecting accurate data is essential to move the risk from real to potential. Financial penalties also exist for facilities when a child develops a hospital acquired injury greater than a stage II. This penalty system is already being implemented in both the USA and Australia.

The introduction of three new stages in the EPUAP and NPUAP guidelines for pressure injuries has seen a greater understanding of the potential for injury in the hospitalised child. After recent research conducted at the RCH the Glamorgan Risk assessment Scale for screening the risk for pressure injuries has been implemented statewide. This screening scale is also in use in the UK. With a common denominator of the same tool, collation and sharing of relevant data between the UK and Australia will be easier to interpret and compare. The accuracy of data collation is also in the early stages and at this point in time inconsistent because of the nursing and allied therapist's general understanding and education of the national staging of pressure injuries.

Stomas including ileostomy, colostomy, MACE, Mitrofanoff, Urostomy/ Vesicostomies and Gastrostomies are, unfortunately, a part of many children's and family's lives. A stoma is an opening that connects a portion of a body cavity to the outside of the body. In all of the above cases, excluding gastrostomies, it is to facilitate waste from the body. Gastrostomies are to facilitate the passage of food to pass directly into the stomach. A gastrostomy is indicated when the child is unable to meet their nutritional requirements orally. The indications for surgery for other resultant stomas are many, uncontrolled inflammatory bowel disease, necrotizing enterocolitis in pre-term infants, obstruction from growths or tumours, diversions for treatment of wounds of the perineum and trauma all contribute to the reasons for surgery. Chronic constipation of unknown etiology, neurogenic bowel and bladder and outlet obstruction are also difficult to manage long term and are in some instances indicators for ostomy surgical procedures. These stomas facilitate the passage of bowel or bladder contents safely out of the body. In paediatrics, many of these temporary stomas are reversed within 2 years. Again the reversal process is not easy for the child and family and early discharge home to an environment both with the Ostomy and following the reversal is the optimum goal. To achieve this early discharge, appropriate measures should be in place from the initial introduction of the necessity for the surgery to the discharge planning and education. While some children and their families cope well with the procedure many struggle with the decision for surgery and the resultant outcome.

Gastrostomies formed for feeding a child directly into the stomach are also usually a longer term solution with many children transiting to adult services with these stomas. Also the formation of a

MACE and Mitrofanoff is usually considered a long term intervention to address incontinence in specific conditions.

In Australia the nursing education and support for these children is acknowledged as important however is somewhat ad hoc. Stomal Therapists attend to these children either as inpatients prior to surgery or at outpatient clinics. In some instances however these children and their families may omit this phase depending on the acuity of admission and in the instance of the newborn may be totally unaware of any support. Again in some of these instances a slightly longer length of stay is expected. Establishing a routine at initial interview and early notification has been noted to decrease this length of stay. The Royal Brisbane and Women's Hospital has a well established team of trained nurses to support and guide parents through this phase of dealing with infants requiring life Ostomy surgery. Although this service is evolutionary in nature, set guidelines can only enhance the delivery of care to ensuring all support, information and education is available to parents.

While surgical **wounds** normally follow a standard trajectory of healing progress, complex wounds are those that present usually unplanned via a trauma or insult and require more detail in the planning and management for extended periods of time. Other wounds fall into the category of complexity because of the treatments for underlying conditions such as childhood cancers.

At the RCH many of the complex wounds are congenital, follow insult from trauma or are stuck in a healing phase. Again accurate data regarding the treatment options is limited and a true and updated clinical pathway is required. The introduction of technology and IT applications, APPS, to assist in streamline the care and interventions of wounds is ideal. We are fortunate at the RCH to be in possession of 3 dimensional cameras to track and map the progress of a wound. While these cameras give current details of the volume and depth of the wound the optimum dressing choice and technique is determined by many staff members and consistence in choice and application is sought. King's College Hospital is a leading force in current best practice trends in wound care and many lessons can be learned from this environment.

Cincinnati Children's Hospital Medical Centre (CCHMC) is a Magnet hospital recognizing the highest achievement that Registered Nurses in healthcare can earn. It has 598 registered patient beds and has over 30,000 admissions per year. It is one of the largest most comprehensive and respected paediatric hospitals and research centres in the United States and has become a world leader in quality improvement.



The International colourful wall at Cincinnati Children's Hospital

I commenced my Fellowship in Cincinnati Children's Hospital Medical Centre (CCHMC) on International Nurses day 2014. I was greeted by security staff at every entrance with the pledge to keep those inside safe. As Cincinnati Children's Hospital is world renown for recognition, prevention and management of risk, although initially daunting, their presence was no surprise. I was met by my wonderful host, Julie Rogers who assisted me with everything I could have wanted.

I started the visit with the GE Intestinal Rehabilitation and Transplant Outpatient Clinic. This world renown centre for paediatric gastro-intestinal tract (GIT) transplant also attracts international patients and on the day of visit 2 such patients were attending. Candid conversations were had regarding the expected availability of these transplant organs which I found quite confronting

however on reflection, necessary. The CCHMC reports a fair/reasonable success rate with small intestine + liver transplants with >50% survival at 1 year. Australia is in the infancy stages of small bowel + liver transplant in children with the first transplant taking place in Melbourne in 2012.

The clinic staff consisted of a Nurse Practitioner (NP), Social Worker, Dietician, Medical Fellow, Enrolled Nurse and Staff Consultant. The clinic saw 5 patients, 3 with Short Gut awaiting bowel/liver transplants. The clinic NP takes a full history including medications and blood results and inputs this data into the integrated electronic medical record (IEMR). Prior to each consultation a short discussion or rounding takes place and a full review of the child's history, as well as current medical issues is had with the treating team. A general plan is outlined and this then guides the consultation with the child and family. All data is real time entry. There appears to be little duplication of notes and discussions and despite this the consultations did not appear to be rushed, rather, concise and comprehensive. The discharge plan is determined and the NP sends off scripts to the family local pharmacy for issue, thus decreasing the wait time and dispensing costs for the hospital.

The USA health funding is one of complexity and can be difficult to understand at a glance. In many instances the health funds appeared to dictate to the treating medical teams the availability of certain treatments and pharmaceuticals. Most of the families visiting have health cover, often supported by employee programs so this did not appear to be an issue with any of the children I encountered. In the instance a family does not have cover, an arrangement is made with the treating hospital and the family to ensure the child is treated and not compromised.

During the GE clinic I also saw the regular changing of feeding devices. This is also standard practice at the RCH however in the USA the health funds supply many of these devices. The device of choice is a smaller lower profile device than those at the RCH. These particular devices will shortly be available in Australia.

CCHMC and the RCH share the concept of Zero Harm to children in our care and Prevention of Pressure Injuries is National Standard 8 in Australia. Financial penalties, both in the USA and Queensland currently exist as a motivator to ensure the potential for injury is addressed. A recent study at CCHMC revealed that more than 10% of children in the intensive care unit experiences pressure ulcers. With this information on board the hospital formed a quality improvement (QI) collaborative leadership team and implemented a QI bundle of solutions. The goal, and the result, was to reduce pressure ulcers among children hospitalized in the pediatric intensive care units by 50 percent within one year. This study was led by Marty Visscher, PhD, Director of the Skin Sciences Program.

Other initiatives around the hospital are traffic lights systems where the parents are informed they are entering a red light zone for pressure ulcers (and other high risk complications) and to initiate conversation with the staff as to what this means for them and their child and what action is needed to prevent harm. The skin integrity team has also identified, as standard practice, any child having surgery of two hours or longer is to have preventative pressure relieving dressings covering specific points. To date this information is not yet published however the nurses report that this has been an effective method of preventing these ulcers from starting in the surgical environment.

Urinary and faecal incontinence is an issue facing many parents of children with a diagnosis of e.g. neurogenic bowel and/or bladder, Ano—rectal malformations (ARM), Hirschsprungs disease, surgery and trauma and slow transit constipation. When I attended the Spina Bifida clinic where children were assessed and managed, bowel and bladder issues were also addressed. The RCH runs a fortnightly Spina Bifida Clinic similar to the CCHMC. Bowel incontinence appeared to be addressed a little more conservatively here with many children taking oral aperients and soiling frequently during the day. While this management is also used at the RCH, faecal continence is the preferred option and is indeed sought for this group of children. This may however include the option of surgical procedures. MACE procedures are not considered as often with this cohort of children at the CCHMC as they are at the RCH, however a more common alternative appears to be the formation of an Ostomy where faeces and urine is passed into an appliance on the abdominal wall.

Risk prevention is a dynamic priority for the CCHMC and this was evident in every situation I was exposed to. CCHMC believes the voice of the family is a powerful motivator for change. Frequent rounding, specific summary reports on risk or potential risk and patient status, projected outcomes, planned care and discharge planning are conducted with both the staff and the family. These are differentiated between family centred rounds and staff risk rounds. I attended both of these rounds while here. The family centred rounds were conducted at the patient bedside with the parent s present. There appears to be a general expectation that a member of the family is present during this time to contribute to, question and understand the child's care. These ward rounds are conducted at a set time and are attended by the entire team of treatment professionals, including allied health professionals, nurses at every level of care and medical staff. On the occasion the carer or parent is not available each child has a journey board in their room to be used as a communication board so clear and concise information is shared in a timely manner. This opportunity encouraged the parents not to hand over care but to be an active co-contributor to their child's planned treatment options. At no point in time did it appear that the hospital staff were working without the parent alongside them. I did not witness any animosity between parent and staff in relation to the care of the child while visiting.

With the total engagement of family centred care the hospital has encouraged each family to use the My Chart application. Here parents can directly access pathology results, appointments, the treating team, physicians and nursing staff and share up to date information with their local G.P. As CCHMC is situated in the middle of Pennsylvania and Indiana some of the children presenting are visitors from out of the state of Ohio. The My Chart access is a paradigm shift where the parents continue control of the health of the child with current information no matter where they are.

A supportive IT profile for many of the departments is also important. All departments are listed on the hospital web home page and the members are identified by both profile and photograph. This assists the parents to familiarise themselves with the person they may be speaking with or will be making personal contact with. The Home page also has direct contact numbers and eliminates unnecessary phone queuing. Each service has a system that attends to messages within a certain time frame. Also on these profile pages specific research information is published and departmental achievements are acknowledged. This page also assists in lifting the professional profile of not only the hospital but also the service. The CCHMC believes that data and true stories reveal the need and build the will to change for the better.

Nurse Practitioners work both independently and along side teams here and many of the staff have trained to extend their practice in this field of nursing. The proposed planning of discharge times are sent through to the wards the day prior to ensure all children are ready for this transition to home or extended care. Criteria lead discharge is encouraged however is still being developed here. Phone call consultations take place when required and discharge post-op phone calls are made by the CN or NP at day 1 and day 4 post-op. A post-operative instruction sheet is also standardized and given to parents on discharge.

From Cincinnati I flew across the North Atlantic Ocean via a pleasant and relatively short 9 hour flight to London. Here I attended **Great Ormond Street Hospital (GOSH)** for children. Opened in 1852 with just 10 beds this hospital is dedicated to "the child first and always". It boasts the widest range of specialist under one roof and is the largest centre for paediatric research outside North America. The international reputation of GOSH overwhelms the modest entrance however once inside I was greeted by the most passionate and dynamic staff. GOSH also accommodates an adolescence ward and services are provided for these children and their families to assist with transition to adult care.



The Stomal Therapist CNC Helen Johnson was my host and she assisted with my schedule, attempting to meet my every request. Helen oversees a small team consisting of one gastroenterology nurse and another stoma nurse. A tissue Viability CNC also works in collaboration with Helen and assistance and discussions are held when peer advice is sought. This team attends to all complex wounds, bowel and bladder issues and Ostomies throughout the hospital.

I attended outpatient Urology clinics and a Cloacal Abnormality clinic with a Multi-disciplinary team (MDT). At the Cloacal MDT I was encouraged to see a psychologist present to discuss with the parents the confronting complications regarding sexuality and the issues these children will face. This discussion was respectfully undertaken one-on-one with the families and followed great discussions by team members. Future planning was also undertaken and surgical options for these children were outlined. The MDT environment was one of challenging discussion and respectful acknowledgement of all members of the team with the child and family foremost.

I was also fortunate to spend an Operating session (formation of MACE) with Mr. Curry (General Surgeon) and then follow up the child post-op with Helen both as an in and out patient. Again GOSH has different treatment bowel flush solutions for children with bowel continence issues and I am keen to explore these further when we are established in the LCCH. MACE or ACE is a standard surgical procedure to facilitate the evacuation of the bowel via a conduit, usually the appendix, in the ascending colon. To date a perfect solution is still to be identified. GOSH often use a solution of Bisacodyl with N/ Saline however restrictions apply with its usage and results vary. The RCH does not use this solution. The need for further research into the most effective solution with the presenting condition is certainly required for optimum treatment. Helen also introduced me to the benefits of a barrier crème to assist with the treatment and pain management of Incontinence associated dermatitis, IAD.

Children with bowel and bladder issues, some requiring surgery, are also seen regularly at GOSH and the hospital caters very well for these little ones. Videos and age appropriate booklets are prepared by the staff and children attending the hospital to get authenticity and factual information regarding procedures and admissions. The hospital is also well resourced with information booklets from many companies. These booklets are not readily available in Australia and I intend sourcing them in future. The urology nursing service is well staffed and the advanced practice nurses conduct specialized procedures prior to outpatient medical clinic visit to ensure all information is at hand. On discharge supplies of catheters and specialised stock is made available from the local GP or district. The method of ensuring children receive their supplies from their local GP or district makes good sense and again this I will be exploring further.

Timely discharge planning contributes to the rotation of children and at GOSH discharge planning is a synchronized schedule. As the tertiary facility discharges back to local districts, home and districts nurses provide much of the follow-up in the home environment. This service is very well established in the UK and due to this the anticipation of returning home appears lessened for many families. I believe this service is currently under-utilised as this relatively new service in Brisbane however am keen to engage it more extensively shortly for localized support. The engagement of the Hospital in the Home, (HITH) nursing service requires adequate guidance to continue caring for these children at an earlier discharge date than that would be expected should they remain an inpatient for this treatment option. The UK delivers a high quality home and community nursing service and brings the children into wound clinics on a much more infrequent basis. Outpatient wound review clinic also operate and continue with the review and planning of ongoing treatments. The funding and research has also been established to guide practice and in some instances to a much more economical and sustainable dressing choice.

The insertion of a Gastrostomy device here is considered only after the first choice of a small PEG tube. Staff and parents report ease of use and less complications with this small tube and the longevity of the tube is extended beyond that of a device. Should the parents opt for a low profile device they are taught how to change a tube when they are comfortable. Trouble shooting information is also available both on the web and in brochure form. Helen, Monica and Tricia spent a great deal of their time explaining the uses and types of specific tubes they use and the benefits of each. Again I am keen to research these further with out GE. CN. The staff attempt to standardize all tube sizes if possible to reduce confusion when sizing a tube and to ensure adequate stock availability. Emergency tubes are often given to the parents once they are

comfortable changing the tube thus eliminate the need to present to the hospital for this relatively simple procedure.

I attended the complex wound care of a young girl with inflammatory bowel disease presenting with resultant fistula. The complexity of the dressing the wound was exacerbated by her ventilation status and pain so a long term dressing option was considered. Consultation from the treating teams was consistent as wound healing progress was slow. Another child was treated in the wound clinic for a chronic arterio-malformation wound. Her frustrations were escalated by just wanting to be "a normal" adolescent.

GOSH provides an updated webpage identifying most of the conditions treated at the hospital and every child, adolescent and parent has access to this. Departmental and staff profiles are also updated. This user friendly home web page is one of the most comprehensive and functional I have seen with ease of navigating around the site geared to both the novice through to the expert. Again achievements and useful links are available. It is directed to specific age groups when necessary and gives departmental contact details. In today's age of instant information and technology the need for accurate and factual information regarding a child's condition from a reliable source is imperative. Here GOSH takes control of the information and offers it up in a modern colourful easy-to-understand way. Parents are often directed to the web page for information on fasting and preparation for admission.



Peter Pan and Tinkerbell at the entrance of GOSH

Chelsea and Westminster Hospital (CWH) NHS has just over 430 beds and treats more than 360,000 patients a year. The hospital caters for both the neonate through to the adult and is in the stage of extending the paediatric facilities and services. More than 80,000 children are treated each year.



The Atrium Chelsea and Westminster Hospital

Paediatric stomal therapy and in fact all stomal therapy nursing can be considered as one of the most basic and undesirable roles in nursing. It never ceases to amaze me however when I meet stomal therapists how passionate they are about their job. The desire to assist people with an essential aspect of daily life crosses all barriers. Again I met a wonderful team at CWH. The support network established across the UK is an important arm of the hospital experience. CWH stomal therapist Niamh has been instrumental in assisting to set this network up with a functional and important role for the children when they return to their communities. A UK paediatric contact list of stomal therapist is essential for this transition to function at its optimum, this list is available to all staff who wish to access it through-out the UK. Regular meeting and workshops are coordinated with the direct assistance from medical supply companies.

All of the resources available again have impressed me. Children and parents have access to age appropriate resources and support information for schools and child care facilities. I readily accepted many of these to utilize on my return. The information is concise and easy to follow.

I also attended a Bladder function clinic run by the CNC. This information translates to data supporting ongoing planning when the child visits the urology consultant at a later date. At CWH Gastrostomy management is similar to Australia however at CWH, the devices used for feeding into the stomach are occasionally placed in the bladder and used to functionally drain urine. A small volume of 2.5 mls of water is inflated into the balloon to minimize bladder spasms and irritation. There was one such inpatient case when I visited.

I was invited to the weekly rounding meeting of the Paediatric Surgical team and heard of their treatments of all of the inpatients as well as the neonatal MDT meeting. The information shared here is vital to ensure information sharing and a continuum of care is maintained 24 hours a day.

Childhood constipation continues to be a problem faced around the world and as mentioned earlier MACE procedures have successfully addressed a percentage of suitable candidates. Within this cohort for a few children with an established MACE the optimum level of satisfaction remains average or below average. Some of these children are those with outlet obstruction or have a history of Hirschsprungs disease with continued constipation following pull through surgery. Niamh stated that in a very small percentage of children, CWH is currently placing the ACE outlet in the sigmoid colon instead of the ascending colon and although not enough of these repositioning procedures have been performed, the outcomes for these children looks promising. This surgery will require further follow-up by the treating therapist to assess the impact on this small cohort of children. I left the hospital armed with resources, information and wonderful contacts.

My final hospital visit was to **King's College Hospital** (KCH) in South London. It is one of London's largest and busiest hospitals and has onsite 950 beds. King's also operates the largest liver transplant program in Europe. While here I met with the Nurse Practitioner Kumal who is leading a team of tissue viability nurses with energy, knowledge and skill.



I spent much of the morning meeting with Kumal Rajpaul N.P., and understanding the different teaching modules used for accessing the many thousand staff currently employed by King's. An onus on keeping the patient safe when in hospital is expressed as a shared arrangement with the patient and the staff. Brochures and booklet on how the patient can continue to engage and take responsibility where possible for their own health and outcomes are explained to each patient on admission. On reflection I would love to have had at least 2 weeks at this hospital as Kumal and his staff's energy and resources were clearly matched and had an enormous amount to offer me.

Kumal also coordinates workshops and education sessions for nurses and practitioners in London to update skill and knowledge in skin care and wound healing. The integration of information is also present on encrypted USB ports for staff use. Security measures around these ports mean that only the user may access them and multiply unsuccessful attempts result in all information being wiped from the USB.

"Pressure Ulcer Prevention and Treatment Made Easy Pathway" was also developed for staff. Kumal stated this was a quick reference guide and feedback was positive from all staff utilising this.

The UK offers great support for nurses furthering their education and at King's the ongoing study is both encouraged and supported by the Trust. The advancement of the skill of the staff, and the functionality of the use of NP's in a hospital as large as King's, is necessary. The only way to see over 1 million patients per year is to rely on these advanced nurse practitioners and Nurse Practitioners. The coordination of discharge planning is essential and the NP's work closely here with the patient and the home support to achieve this in a timely manner. Access to work e-mails from home or en route to work supports a bustling network of staff relying on public transport while at the same time eliminating unavoidable down time.

As the end of the hospital visits concluded I was invited to participate in an information session with an **Ostomy product company**. Here I also saw how the companies engage with members of the community. In this instance the company involved provides an afternoon tea information session for people with Chron's disease and Ulcerative Colitis, children with ostomies and community nurses. This is a wonderful supportive network for Ostomates where they can engage with others and support one another along their journey. These afternoons are also attended by registered stomal therapists.

The final leg of the Fellowship was the **WCET in Sweden**. This was a fantastic backdrop for the World Council of Enterostomal Therapist to meet in 2014. Of the many international speakers, Elizabeth English RN STN AM (Australia) and Prof. Keryln Carville, RN STN (Australia) were inspiring. Both were notable recipients of Churchill Fellowships in 1996 and 1995 respectively.



Research from Oslo University Hospital has supported the belief at the RCH and suggested that full continence should be the goal for all children. The method of achieving this is varied however engagement from all people involved in the child's life is imperative. Defecation disorders in children should be identified early however this cannot be achieved until a national "diaper weaning" program is agreed upon. Again a notable inclusion with all of the Scandinavian countries presenting on childhood ostomates was the psychiatrist in the MDT. A belief that one pre-operative visit from the stomal therapist is not enough preparation for the child and family holds sound in Norway.

One of the most rewarding aspects of attending the WCET was the opportunity to network with likeminded people from all over the world. This scenario and those in the UK support that we have a way to go to support the Paediatric nurses of Australia.

Conclusions and Recommendations:

For six and one half weeks I travelled to Hospitals in Cincinnati and London then concluded my research by attending a world conference in Sweden. I have seen children treated, families consulted, nursing staff engaged and entire teams deliver the best of cares. I have been included and encouraged. I have also felt a great sense of pride in acknowledging we deliver world class treatments, interventions and cares in Australia. The resources available to some and not others due to rural diversity and accessibility should not be acceptable in children's health.

With the world becoming smaller due to the advances of technology and access to greater and higher education resources and experts, I can't help think how important the person to person contact has been for me during this experience. The opportunity exists to strengthen the paediatric clinical nursing network both nationally and world wide, to become a leader and a resource for other clinical nurse specialist and to determine to deliver world class care with confidence and skill.

RECOMMENDATIONS:

- Engage QI improvement bundles on wards for PI's and standardize skin inspections with daily hygiene routine. Introduce Skin Integrity rounding in PICU and HDU and OR on daily basis for education and treatment options. Parent and carer information and instructional alerts when children enter an area of the hospital that is classified as Red Alert for potential injury, (Traffic light modified system) i.e. Paediatric Intensive Care Unit (PICU), Operating Room (OR) and High Dependency Unit (HDU). Early discussions with families to engage them to continue the responsibility for primary care when able, to assist nursing service for early identification of pressure risks and injuries. Inclusion of family members to positively engage in their continued responsibilities of care while the child is in hospital, empowering them through information and education on how they may do this. Engage University support for research into bowel disorders.
- Investigate the development of an application for the children and families to assist with owning medical information, organizing clinic appointments and successful transition to adult services.
- Organise an Australian Paediatric Stomal Therapist registration data base to assist with sharing information, identifying research opportunities and improving practice.
- Undertake an audit of our current bowel management regime inclusive of the pre-existing conditions to help determine the best practice for faecal continence following MACE surgery. Follow-up research into descending colon MACE surgery for children with outlet obstruction constipation. Conduct further research into bowel flushes for paediatric patients. Look at routine bowel management for children who will experience extended decreased mobility post-operatively, decreasing further complications and extended stays.
- Undertake a structured GE Nurse lead clinic for routine procedures. Educate GE nurses in specific courses to support the expertise required to attend to these children and transition them into their own environment.
- Provide clinic meeting times for families with common bowel disorders, engage Multidisciplinary Team members.
- Provide information on staff profiles and current research details and contact details for service providers. Ensure easy access to information and resources. External electronic access to information regarding the hospital, staff, procedural preparation and general length of stay to allow parents and carers to access this when required and unrestricted.
- Access to a fully functioning cohort of Paediatric Stomal and GIT nurses Australia wide and link bi-annually with tele-health to share information, data and research. Engage a Tissue Viability Nurse for Paediatrics to ensure specific resources are current and appropriate.

- Routine inclusion of psychological support for all children and their families prior to undergoing body disfiguring surgery improves the coping strategies engaged by this group of children and in some cases reduces hospital length of stay. Have an opt out option rather than an opt in.
- Accessible and dynamic staff and parent training modules which are timely and current improve the buy-in from ward nursing staff and parents to confidently educate opportunistically staff, children and their family. Create organizational tool kits specific to the paediatric population for staff.
- The Clinical Nurse is instrumental in preparing information for discharge via a standardised check list as soon as the admission interview is complete. The Clinical Nurse completes initial patient summary and questionnaire at outpatient clinic visit.
- Nurse led transition modules ensure consistent information, support and access for all children. Nurse lead extended hours clinics generate easier access to nursing procedure appointments for children and their families. Pre-clinic phone calls from CN to ensure all issues are prepared for and appropriate staff are informed. Post-visit phone call regime when required for engagement with family to decrease anxiety and decrease presentations to emergency department.
- The use of Clinical Pathways for standard procedures. Discharge planning and previously arranged discharge times to ensure limited delay in discharge. Engagement of Hospital in the home (HITH) and community links as a standard.
- Journey boards in every room for communication when parents are unable to be present on ward rounds. Engage parents at every opportunity to be involved in the ward rounding.

To choose one highlight is too difficult. Every place and every person had an impact on me, some greater than others, some more personal than others and some just highlighted that we are doing some fantastic work in our own backyard. It is undeniable however that we all share a responsibility to try to improve our practice, to do better today than we did yesterday and to have the vision and drive to improve again tomorrow. With limited resources to achieve this on every level, sharing information both nationally and internationally is imperative to achieve best practice world wide.

TABLE

ACE	Ante-grade Colonic Enema
ARM	Ano-rectal Malformations
CCHMC	Cincinnati Children's Hospital Medical Centre
CHQ	Children's Health Queensland
CIC	Clean Intermittent Catheterisation
CN	Clinical Nurse
CNC	Clinical Nurse Consultant
CWH	Chelsea and Westminster Hospital
EPUAP	European Pressure Ulcer Advisory Panel
GE	Gastrointestinal
GIT	Gastro-intestinal Tract
GOSH	Great Ormond Street Hospital, London
GP	General Practitioner
HITH	Hospital In the Home
IAD	Incontinence Associated Dermatitis
IBD	Inflammatory Bowel Disease
IEMR	integrated Electric Medical Record
IT	Information Technology
KCH	King's College Hospital
LCCH	Lady Cilento Children's Hospital, Brisbane
MACE	Malone Ante-grade Colonic Enema
MCH	Mater Children's Hospital
MDT	Multi-disciplinary team
NP	Nurse Practitioner
NPUAP	National Pressure Ulcer Advisory Panel
OR	Operating Room
PEG	Percutaneous Endoscopic Gastrostomy
PI	Pressure Injury
PICU	Paediatric Intensive Care Unit.
RCH	Royal Children's Hospital Brisbane
WCET	World Council of Entero-stomal therapist
WCMT	Winston Churchill Memorial Trust