Report by Sharon Gilchrist

2011 Churchill Fellow

The Bob and June Prickett Churchill Fellowship to Investigate Comprehensive Epilepsy Programmes including nursing services for children and young people with epilepsy - US, Italy and the UK.

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Signed ….. Sharon Gilchrist …………………. Dated…20.7.12………. 
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INTRODUCTION

Epilepsy is recognised as the most common serious neurological condition in childhood\(^1\). It affects approximately 2% of children and is characterised by recurrent, unprovoked seizures.

Whilst many children will have well-controlled epilepsy with a combination of medication and managing environmental or lifestyle factors, the remaining group of children will have complex epilepsy and a range of co-morbidities, some of which may have existed prior to the onset of their epilepsy, and impact on their developmental progress and day to day function. These children and their families will require frequent and ongoing interactions and support with specialists both within hospital systems and in their community. Multidisciplinary care for children with epilepsy is acknowledged as best practice\(^2\) and all children with complex epilepsy should have access to a comprehensive epilepsy programme, offering the range of options to treat their epilepsy\(^3\) and maximise their quality of life.

As the Clinical Nurse Consultant for children with Epilepsy at the Royal Children’s Hospital, a tertiary paediatric children’s hospital in Brisbane, Queensland, I am part of the Neurosciences Team, which provides state-wide services covering 1,722,000km\(^2\). A large component of the care provision by the team is via the outpatient model and I was interested to compare models with other teams.

I wanted to explore the inpatient models of care for children with epilepsy during various admissions, emergency and elective. I explored the roles and education provided by Epilepsy Specialist Nurses within Comprehensive Epilepsy Programmes including the systems and processes in place to provide efficient and effective healthcare in both hospitals and in their communities.

With the progression towards the Queensland Children’s Hospital [QCH], I was acutely aware that my Churchill Fellowship was also an opportunity to look at the model of nursing within each Comprehensive Epilepsy Programme in order to assist with the direction of nursing as Queensland’s two tertiary paediatric children’s hospitals combine to become the QCH.

With the ability to electronically connect, establishing an international collaborative collegiate nursing network for nursing research, education and support was my final goal. Australian nurses have so much to offer and other health professionals around the world are so keen to connect with us.

Acknowledgements

Thank you firstly and foremost to Mr Bob and the late Mrs June Prickett for having the foresight and selflessness to fund such incredible learning experiences for Australian citizens. I am honoured to be a Dusty Bob Fellow.

Thank you to my two referees Dr Geoff Wallace and Dr Stephen Malone for their generous words in support of the suitability of both my project and myself as a candidate.

Thank you to previous Churchill Fellows who offered generous words of encouragement and advice throughout the entire application process and beyond. Your support is invaluable.

Thank you to those around the globe who participated in interviews and tours of your facility and introductions to others during my journey. Thank you for making yourselves available and for answering my endless questions in order for me to gain a well rounded insight into your service.

To the patients and their families, a special thank you for sharing your story.

To my husband Gerry, my ultimate thanks for you. Thank you for being there for our children while I could not.
EXECUTIVE SUMMARY

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The Bob and June Prickett Churchill Fellowship to Investigate Comprehensive Epilepsy Programmes including nursing services for children and young people with epilepsy - US, Italy and the UK.

Best practice in healthcare is mandatory in order to provide the best long term outcome. All children with epilepsy deserve nothing short of best practice at all times. I was left without doubt that I witnessed best practice when visiting overseas Neuroscience Departments providing comprehensive epilepsy programmes, which had been appropriately funded and established for a number of years. Supported by research, the outcomes for children and young people with epilepsy spoke for themselves. These multi-disciplinary teams, where nursing had a distinct role and voice, have provided me with inspiration for giving the same to Australian nurses who care for children with epilepsy, both at the bedside and in the specialty role.

Of special note, Nurse Practitioners in Miami Children’s Hospital, Pat Dean, Pillar Gennaro and Maria Walke, gave me a fantastic insight into how the Nurse Practitioner model can work both at an inpatient and outpatient level. And Patty Shafer, at Beth Israel Deaconess Medical Centre, Boston, through words and action, demonstrated the importance of nursing and the role of the nurse.

The enthusiasm to share ideas and improve services for children and young people with epilepsy is international, multi-cultural and has no language barrier.

Highlights

- Observing the Nurse Practitioner role in action in a variety of settings
- Observing the functioning of well resourced Comprehensive Epilepsy Programmes
- Giving a lecture about the role of the Australian Epilepsy Clinical Nurse Consultant in Rome
- Independent Nursing outpatient clinics
- Nursing research models in Rome
- Creating an international network of Epilepsy Nurse Specialists

Recommendations

- An Australia-wide competency-based education programme for ward-based nursing staff
- Nurse Practitioner role is further developed in Australia
- Strengthening of the voice of Epilepsy specialty nursing throughout Australia
- Nurse-led clinics are part of all Australian Comprehensive Epilepsy Programmes
- Australian Epilepsy Nurses Special Interest Group (ENSIGA), collaboratively with the American Nurses group, develops a formalised education qualification for Epilepsy Specialist Nurses
- Upgrading the medication systems currently in use in tertiary paediatric hospitals

Dissemination

I will be presenting my findings at local meetings to nursing staff at ward level and at leadership level. It is anticipated that I will have further opportunities to present information at various forums including national and international meetings via poster and platform opportunities and via the national epilepsy nursing group. It is my intention to further publish findings from research.

Prior to the completion of this report I have been engaged to speak at a state-wide education forum, nurse’s education day and an article has been printed in a state-wide Queensland health publication.

I will continue to seek opportunities to promote best practice in epilepsy nursing care and actively encourage others to apply for a unique learning experience through the Churchill Trust.
### PROGRAMME

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| April 2nd - 6th | Miami Children's Hospital  
3100 S.W. 62nd Avenue,  
Miami, Florida 33155  
**Contact:** Pat Dean | |
| April 9th - 13th | Johns Hopkins Children’s Centre  
600 N. Wolfe Street  
Baltimore, MD 21287-6151  
**Contact:** Sarah Doerr | |
| April 16th - 20th | Beth Israel Deaconess Medical Centre and Children's Hospital Boston  
330 Brookline Avenue  
Boston, MA 02215  
**Contact:** Patty Shafer | |
| April 23rd - 27th | Bambino Gesù Osperdale Pediatrico  
Piazza S. Onfrio, 4  
00165, Roma  
**Contact:** Immacolata Dall’Oglio | |
| May 1st - 4th | Great Ormond Street Hospital for Children  
Great Ormond Street  
London WC1N 3JH  
**Contact:** Hannah Chaffe | |
| May 7th - 10th | Royal Hospital for Sick Children  
9 Sciennes Road  
Edinburgh  
EH9 1LF  
**Contact:** Celia Brand | |

My fellowship included attendance at inpatient ward rounds, outpatient clinics, inclusion in day to day ward activities, interviews with staff, meetings with senior nursing leaders and interviews with various members of staff outside of the nursing realm.  
I also had an opportunity to speak with many children, young people and their families, to gain the patient perspective of the services they receive.  
I was fortunate in gaining a well-rounded view of most Comprehensive Epilepsy Programme functioning through the generous opportunities to be present for extended periods in most wards, monitoring units, departments and clinics.
Background
Epilepsy is the tendency to have recurrent spontaneous afebrile seizures. In children, it is the most prevalent serious neurological condition. It occurs in about 2% of the population and has a peak incidence in children in the first year of life [Figure 1], tapering over childhood and into adolescence. Epilepsy is not an entity in itself. Rather, it occurs as a result of an underlying cause.

Possible underlying problems which give rise to epileptic seizures in children are either from inherited or new genetic defects, structural or metabolic disorders of the brain or from a yet unknown/undetermined cause. Understanding the underlying reason for why the seizures are occurring may assist with guiding treatment choices in some instances, avoiding potentially harmful treatments in others, and forms the basis of discussions with families with regards to the prognosis for their child’s future development and quality of life.

![Figure 1: Incidence of Epilepsy across the age spectrum](image)

The current first line treatment for recurrent seizures is medication [Figure 2]. Other treatments include the Ketogenic Diet or Modified Atkins Diet [Figure 3], insertion of a Vagus Nerve Stimulator [VNS] device [Figure 4] or Epilepsy Surgery [Figure 5].

Seizures will be well controlled for approximately 70% of children with a single, appropriately chosen anti-convulsant medication. For the remaining children, a combination of multiple medications, diet therapies and/or surgical procedures are often required to attempt to control their seizures, sometimes with excellent success and sometimes with moderate success. The aim of treatment for all children is seizure freedom without side effects and for some children this can be a delicate balance. For the group of children and young people who have poorly controlled seizures despite maximal therapies, the combination of their underlying condition, multiple seizures and medications has a significant impact on their developmental outcome and in many instances their quality of life and lifespan. The recently released Epilepsy Across the Spectrum, 2012, reiterated Hoie’s 2008 population-based study which recognised that regardless of level of control or moderation of seizure activity, epilepsy is multifaceted and often co-morbidities exist with the condition. Therefore in order to meet the ongoing needs of the children and young people across all ages and stages of development, a variety of different but complementary services are required.
Figure 2: Anticonvulsant medications introduced to the market 1853 to 2009 [Shorvon 2009]

Figure 3: Ratios of Carbohydrate to Protein and Fat in Modified Atkins, Ketogenic and Normal Diets
Parenting a child brings challenges to all those who undertake it. Parenting a child with additional needs, such as epilepsy, brings additional challenges. For children with epilepsy, some of the additional challenges for the child may come in the form of social, emotional, psychological and cognitive challenges. Epilepsy may be perceived with stigma by some and may especially impact young people in their late teens as they seek their first employment position. There are considerations for young people with relation to driving motorised vehicles and at when considering reproduction. Furthermore, for the family of the child, there may be additional financial strain depending on the nature and severity of the child’s condition, stress on the parental relationships and an impact on the sibling relationships. A possible influence of planning for additional children within the family unit is possible if the cause of the underlying condition leading to epilepsy has a genetic focus. Regardless of the severity of the child’s epilepsy, the impact within each family unit is as individual as each family itself.

In Queensland, as in many parts of Australia, children with epilepsy are managed by neurologists, general paediatricians and general practitioners or a combination of all three. Comprehensive epilepsy programmes are considered the gold standard of treatment for children with complex epilepsy² as they offer the full range of multi-disciplinary services for children and young people with epilepsy. Although the definition of complex epilepsy varies, there would be little argument with saying that children who are on more than 2 medication and not completely seizure free, those with additional concerns, either health, physical, learning or emotional, would be considered to be complex. These children, their family and their local treating team are best supported by a complex epilepsy programme, which encompasses a variety of specialty services to address the needs of the child, family and also supports the child’s primary treating team. For children with well-controlled epilepsy, a minimum of at least a yearly review by a specialist is recommended by the Scottish Intercollegiate Guideline Network [SIGN]. This yearly assessment is to facilitate identification of problems, discuss weaning of medications if appropriate and minimise the risk of the child or young person being lost to follow up, especially in the transition years between paediatric and adult services.
Comprehensive Epilepsy Programmes by inference of their title suggests a suite of services for children and young people who have epilepsy. The implication is that there will be an offer of access for the families of children with epilepsy to the appropriate services and personnel as and when the need arises. Each child would receive expert assessments in the diagnostic phase, a plan for active treatment would be generated in conjunction with the family and plans for long term management of the child’s conditions would be facilitated with the child’s other treating professionals.

Comprehensive Epilepsy Programmes would therefore include a range of equipment, facilities, staff and funding to provide a range of services including:

- Specialists Clinics
- Diagnostic Imaging – e.g. MRI, PET, SPECT
- Medication management
- Patient Education
- Social and Emotional Support
- Inpatient Epilepsy Monitoring Unit [EMU]
- Ketogenic diet
- Vagus Nerve Stimulation implantation or other implantable medical devices
- Epilepsy Surgery
- Rehabilitation and Allied Health

Whilst there are guidelines to encourage best practice in epilepsy care, there are no absolutes as to how each Comprehensive Epilepsy Programme in Australia was/is to be funded or configured, nor is there true incentive for collaboration between states with regards to lobbying for setting up identical services in each state of Australia. Hence, there is an inconsistency between the states with regards to what is available for patients and crossing of state borders in search of services for patients occurs by both families and professionals, albeit with the best intentions.

The roles and functionality of nurses and nursing within Comprehensive Epilepsy Programme teams also varies within Australian Centres. Some centres have specialist nursing services provided solely via hospital funded staff whilst others are supported by specialist nurses from community agencies. Yet others have a combination of both. Further to funding, the roles of each nurse can be from generalist, providing a wide range of supports to children and young people and their families, to nursing roles which cover very specific aspects of epilepsy care e.g. Ketogenic diet, VNS or epilepsy surgery. The roles of each of the nurses within Australian Epilepsy Programmes have either been created as specific roles or have been evolutionary in nature, something I was interested to explore while on my Churchill Fellowship travels.

Nursing specific education for paediatric epilepsy specialist nurses is a challenge in Australia. Limited courses have been available in the specialty area and international courses are often adult focused and cost-prohibitive. The Nurse Practitioner model for advance practice nurses is also in its infancy compared with overseas countries. Education for ward-based staff caring for patients with epilepsy in all states in Australia varies greatly. There are currently no Australia-wide nursing standards outlining the minimum requirements for nursing care for a patient with epilepsy although the nursing special interest group [ENSIGA] has been collaboratively developing a national guideline for a care of the patient in the epilepsy monitoring units throughout Australia.

So with an understanding that in Australian states all is not alike, I set off to explore the scope of nursing practice for nurses in the USA, Italy and the UK in specialist centres. How did nurses in these countries practice and what aspects of best practice for children and young people with epilepsy could be adapted for Australia?
Fellowship Programme
Miami – Florida
The first leg of my journey began in Florida, the south eastern tip of the United Stated of America, in the well established Neurology Department at the Miami Children’s Hospital. Founded in 1950, Miami Children’s Hospital has 275 paediatric beds including 30 beds in their dedicated Neuroscience Ward for patients aged 0 – 21 years. The Comprehensive Epilepsy Programme, under the umbrella of the Brain Institute, was first established in the 1980’s by its current director, Dr Michael Duchowny and the team which cares for children with neurological conditions includes a variety of medical and nursing specialists and physician assistants. There were obvious strengths in their surgical programme and the nursing staff showed their knowledge and confidence in caring for the children and young people undergoing the procedures in all phases of the process.

Care for children with epilepsy is provided through a combination of outpatient and inpatient care. Due to Miami’s physical location and expertise at the centre, the catchment area for the service is large and varied, often taking in children from the local area, South America, other areas of the US and overseas. Miami Children’s Hospital has also been designated an American Nurses Credentialing Center (ANCC) Magnet facility, the nursing profession’s most prestigious institutional honour in America, and nurses in the ward have participated in this programme as part of their professional development. They proudly display their achievements.

The service offered all aspects of management for children with epilepsy including the full range of diagnostic assessment, medication management, Ketogenic diet, surgical programme, additional supports including neuropsychology and allied health support. Vagus Nerve Stimulation [VNS] did not feature prominently within the service although staff indicated that it was available if the patients were interested in pursuing it for their child.

During the week I visited the Miami Children’s Hospital [MCH], I spent time in both the inpatient and the outpatient department. On the inpatient ward, the structure comprises of a Nursing Director, who covers 2 wards/floors, a Manager, who is responsible for rosters and budgets, 4 Clinical Nurse co-ordinators, a number of Charge nurses, general ward nurses and care assistants. There was also a Nurse Educator assigned to the unit to support the education and learning needs of the nursing staff. In addition to this, there were specialty Nurse Practitioners who worked in this Neuroscience Ward and outpatient areas, including the 3 from Neurology and 2 from Neurosurgery.

The mornings commenced on the inpatient ward with a daily neurology team review of EEG data for the patients who are currently inpatients for long term video EEG monitoring [LTM] and followed by a ward round including Consultant Neurologist and Nurse Practitioner and other staff members, visiting each patient, making plans for their ongoing stay or discharge. The Nurse Practitioner [NP] role was then to manage the care of the patients in conjunction with the staff on the ward. The NP’s on the Neuroscience Ward at MCH showed exceptional leadership skills in providing direction, advice and support for the nursing staff on the ward, adjusting medication orders where needed and ordering tests where required. Their practice in caring for the patients and their families was outstanding and the model of service for an inpatient unit was enviable. Whilst one NP, Pat Dean, was clearly the lead NP in the role of inpatient care, there was strong collegial support from the 2 other NP’s Pillar Gennaro and Maria Walke.

With multiple patients being admitted daily for LTM between Mondays to Thursday [approximately 13 patients per week], the inpatient unit has a very high turnover of its beds and therefore must be run efficiently. The impact of insurance funding is also evident in these processes, with additional approvals needing to be sought if an overstay was anticipated or the financial impact was discussed if a patient was to stay longer than expected and approval from the insurance company was not expected to be granted. The NP balanced financial management and patient needs as part of providing a cost efficient and effective service.
Nurse Practitioner Pat Dean response to the question “What is the best part of your job”?
“Taking care of amazing patients. Interacting with families. How patients and families deal with their condition with grace and dignity. The friendly atmosphere on the ward and the doctors are very supportive of my role and of research projects.”

For nurses who work on the ward, a structured programme of education exists on commencement of employment via attendance at the Nursing Academy, for 4 days of lectures on various aspects of neurological conditions over a one month period. In addition to this, there are specific modules which each nurse is expected to complete within a 3 month timeframe.
To assist the nurses in their day-to-day work, Mosby Nursing Skills®, a generic version of nursing standards, is available electronically within the ward on mobile work stations. This helped novice nurses by providing readily available resources at the bedside to assist with the care of the patient.
Nurses on the ward are currently participating in a retrospective research project and several research projects have been completed over the previous 3 years. Nurse-led research is encouraged at MCH, which has its own research council with ward representatives.

Most contrasting to most of Queensland, and many other hospitals in Australia, were the medication systems for inpatients, first viewed in MCH and further experienced in the hospitals in the US. The Pyxis System® [Figure 6-9] for medications and intravenous fluids is a commercially branded system for managing the dispensing of medications for patients in ward environments. This system provided an electronic version of what is traditionally the second person in the ‘double-checking’ procedure in a paediatric hospital. With a quoted error rate of 1%, the time efficiencies for nurses were evident, but more importantly, the patient safety factors inbuilt into the system, with its individually bar-coded medications and bar-coded armbands for children, demonstrated a superior leap forward from the current system of “multiple medications in a pantry-style cupboard system” which still currently exists in many wards and hospitals. Repeatedly watching nurses using these systems, with their inbuilt safety mechanisms, in 3 different hospital settings challenged me to think about the procedures that we have for administering medications to children in tertiary hospitals in Australia, where the children, due to the nature of their illness or disease, are often receiving multiple medications throughout the day. Could we make it safer for children, reduce the risk of error and make medication administration more efficient for the nursing staff performing these tasks, by using a similar system?

Figure 6 & 7& 8: Pyxis® Medication System

Figure 9: Individually barcoded patient armband
I was privileged to be able to sit in on 2 outpatients clinics during my week in Miami. One was a combined Neurogenetic-metabolic clinic attended by both a treating Neuro-Geneticist and a Nurse Practitioner. The families were seen by both members of the team during the one visit as well as Neurology Fellows. Each of these children had their own treating neurologist or primary care physician outside of the clinic was viewed as a super-specialty clinic, usually a one-off visit. As with many families who attend the hospital, many of the patients only spoke Spanish, a quality that is helpful in many of the bi-lingual staff. The NP role in this clinic was pivotal in taking an excellent history and being part of the explanation and education to the families about their child’s condition.

Other highlights from Miami included the transcranial stimulation unit, Spanish translations, Ketogenic diet discussions, morning review of EEG data, discussions with the Ward Educator and Valet parking for patients.
Baltimore – Maryland

My fellowship journey continued to Johns Hopkins Hospital in Baltimore, Maryland. Johns Hopkins is steeped in tradition, opening in 1889 with its mission to “improve the health of our community and the world by setting the standard of excellence in patient care”. Care for children with epilepsy has been provided at Johns Hopkins since the early 1900’s and the team has grown steadily to currently comprise of a combination of paediatric and adult specialists, who work together to provide care for patients both on an inpatient and outpatient basis for all aspects of epilepsy. My overall impression was that staff have a sense of ‘belonging’ to the Hopkins family.

Johns Hopkins Hospital has 1000 beds in total, with 205 paediatric beds, priding themselves in providing the full range of services for children and young people with epilepsy including diagnostic workup for children following first seizure/s, full management of patients who are maintained on medication for their seizures, a complete epilepsy surgery programme, Ketogenic diet programme and VNS service. They have an affiliation with the Kennedy Krieger Institute, adjacent the hospital which provides rehabilitation services and support on an ongoing basis, whilst being a stand-alone Institute in its own right.

Some strengths at Johns Hopkins were obvious such as Ketogenic Diet programme, with Dr Eric Kossoff making himself available to discuss both the Ketogenic diet and Modified Atkins Diet programme processes. I also had the opportunity to be present in a Ketogenic diet second opinion clinic, an invaluable experience, as well as a group Modified Atkins Diet class for young people about to commence this diet. Others strengths at Johns Hopkins were more subtle, such as the apparent seamless transition between paediatric care and adult health care at the hospital or to other facilities of their choosing.

The paediatric and adult medical and nursing teams work alongside each other within this facility. There is a combined epilepsy monitoring unit [EMU] for all ages with children undergoing epilepsy monitoring in the adult environment prior to surgery and in the adult intensive care unit following surgery. Only when well enough do the paediatric patients return to the paediatric environment to recuperate, prior to being discharged home.

When I met with the Nurse Unit Manager for the Monitoring Unit, Noelle Stewart, this patient age range was one of the challenges that Noelle indicated as a consideration when making bookings for the 375 patients which are admitted through the unit each year into the 6 hard-wired monitoring beds on the adult Neurology ward. Additional special care items of equipment had been purchased to address the needs of paediatric sized patients and nurses on the unit had additional education in the care of paediatric patients. Despite this, there was still an ongoing level of discomfort for some nurses in caring for children in an adult ward which was unlikely to change, as despite the move to new wards in the Sheikh Zayed Tower [Figure 11] and the Bloomberg Children’s Center imminently after my visit, the model of service was to remain the same.

Whilst there was a lack of a formal transition programme for young people within Johns Hopkins, there was also no apparent pressure to transition young people for a variety of reasons according to Rebecca Fisher, Nurse Clinician with the adult team. There didn’t appear to be the inherent problems with transferring of patient history, information, data etc. that is often experienced by patients when they transfer to adult facilities and Rebecca was unaware of any issues faced by patients in this respect, possibly because all patient records were electronic. For children and young people who were approaching adulthood, the option was available to remain with their current neurologist for an extended time or transfer their care to another provider on reaching the age of 17 years, and processes were in place to transfer the information to the health care provider, but if a more formal transition support programme was required, a community support agency was likely to provide this. Rebecca identified a number of agencies who supplied these programmes as the unit did not have their own dedicated social worker to provide this service, nor did the specialist nurses provide this.
As with Miami Children’s Hospital, at Johns Hopkins the impact of individual insurance funding on patient services was evident. For example, Positron Emission Tomography [PET] scans, part of the pre-surgical assessment for epilepsy surgery, would not be approved as an inpatient occasion of service by one insurance funding body, despite the impost this posed for families, who would also have an inpatient stay for various other aspects of their pre-surgical assessment. Part of Rebecca’s day was routinely allocated to contacting insurance companies advocating for patients within her care. But insurance funding would prove to be a two edged sword, as with the more patients that were brought into the service for care, and with smart business acumen combined with government and non-government funding and strategies for managing patients without insurance, so the services also grew; and this was witnessed in all centres across the USA that I visited. My thoughts were stimulated about applying sound business strategies to public health systems to improve the outcomes.

During my stay in Johns Hopkins, I was fortunate to spend an extended time with paediatric Nurse Practitioner Sarah Doerrer, who had joined the team 4 months prior to my visit, taking over the position from the previous NP. Sarah conducted a First Seizure clinic at Johns Hopkins twice a week and whilst I was unable to sit in on the clinic, Sarah was generous in sharing information about the clinic functioning and processes. The First Seizure clinic was for children 0 – 17 years who have had a seizure within the previous 30 days and resided in the state of Maryland. The children attend the clinic after a review with their GP or primary physician, the American equivalent of an Australian Paediatrician, but are excluded from attending this particular clinic if they have also seen a Neurologist or NP. The child would have an EEG in the morning before the clinic and would see the NP in the clinic in the afternoon. The model of service involves independent practice by the NP but support is available from a Neurologist attending to his/her own clinic within the same outpatient area, should it be needed. These First Seizure clinics had been successfully running for a number of years at Johns Hopkins and the overarching NP model of care is well established in the US. From the data collected to date, it was rare for medications to be started for the patients from the First Seizure clinics and patient satisfaction and outcomes supports the clinic continuation.

During my interview with Nurse Manager of the Infants and Toddlers Ward Dorte Thorndike, we discussed the 12 week orientation programme for new nursing staff at Hopkins. This programme involved 2 weeks full time in classes followed by 10 weeks on the ‘floor’ with a preceptor, following a pre-determined checklist to ensure that the nurses are exposed to children with a variety of conditions and situations, including children with seizures and epilepsy, while being supported during this intense learning phase. The nurse to patient ratio in this ward was usually 1:3. This structured programme and support for new nursing staff contributed to Dorte feeling that ‘working at Hopkins was a privilege and a place to grow’.
We also discussed the emergency response processes in place for children with prolonged seizures and I was interested to hear that families are able to activate the alert for the Rapid Response Team [RRT] if they feel that their child is deteriorating and that they have not received a response from the medical and nursing staff in the ward/floor that they feel is appropriate or sufficient. In most hospitals, it is the staff who would usually alert the emergency response team, whereby at least 6 experienced intensive care and emergency medicine medical and nursing staff are called to the assistance of a child who is already an inpatient within the hospital and who has become very ill suddenly. At Johns Hopkins, the chaplain also attends these emergency calls to provide support. Dorte believed that the parent initiation RRT had begun approximately 5-6 years ago and although not activated often, it had proved very successful.

Other highlights from Baltimore included attending the Neurology Grand Rounds with piano accompaniment, Epilepsy surgery conference meeting, Paediatrics Neurology Grand Rounds, a tour of the neurology ward, tour of the EMU, tour of the Kennedy Krieger Institute and a tour of the new wards within the Sheikh Zayed Tower and the Bloomberg Children’s Center prior to opening including discussions regarding how to move patients from one facility to another, important information for the move for Brisbane’s tertiary hospitals in the lead up to the opening of the Queensland Children’s Hospital in 2014.

Boston – Massachusetts
Travelling further north, my fellowship led me to the Beth Israel Deaconess Medical Centre and the Boston Children’s Hospital. Located within a medical precinct which includes Harvard medical school and several other medical facilities, The Beth Israel Deaconess Medical Centre [BIDMC] is the culmination of the 1996 merger of 2 separate adult hospitals, each with their own unique but medically noteworthy history, dating back to the late 1800’s and early 1900’s. BIDMC Neurology Department is a very large department caring for adult patients, 18 years and over and within it, the Comprehensive Epilepsy Team includes 10 epileptologists and 2 Nurse Specialists. The Boston Children’s hospital is a private hospital, opening in 1869 as a 20 bed unit. The Boston Children’s Hospital epilepsy programme has been in existence since 1944 and claims to be historically the first paediatric Comprehensive Epilepsy Programme in America.

My visit at BIDMC was with esteemed Epilepsy Nurse Specialist and Researcher, Patty Shafer who, through her words and actions, reminded me of why I am a nurse and the importance of nursing. The model of service in BIDMC for nursing is different than the 2 previous hospitals in the US that I have visited. Due to the large number of Neurologists that visited the hospital, which could number up to as many as 50 over the course of a year, Patty, and fellow Nurse Specialist, Dianne Sandstrom, only accepted referrals from the Epileptologists within the service, of which there were 10. This contained the workload to a manageable quantity and ensured that there was some clarity around the services that were provided by the nurse specialists.

There were at least 6 independent Nurse clinics each week at BIDMC. Patients in the clinics included all patients prior to their admission for VEEG monitoring. Other attended for pre-surgical appointments, general epilepsy management and pre or post VNS insertion including device setting changes. As memory is identified as a concern for many patients with epilepsy, a printed summary of the key points from the clinic visit was provided to each patient prior to them leaving. This also included their medications and doses and any proposed changes.

There is currently no dietary programme at BIDMC for patients with epilepsy but there is a significant VNS service in place. Due to the model of care and services provided by the nurse specialist, including a full VNS service, most patients see the nurses in clinics twice as often as the epileptologists. Patty
highlighted the challenges again with the insurance funded system in discouraging multidisciplinary clinics or multiple appointments on the same day with the same team, which benefits the patient in many ways, but which were viewed as ‘double-dipping’ by the insurance company and therefore not funded.

At Boston Children’s Hospital, both the inpatient Neuroscience ward and the outpatient ward have a significant number of nurses dedicated to the various aspects care of children and young people with epilepsy, all of whom have wealth of experience and enthusiasm. The inpatient unit is a 26 bed ward with 6 hard-wired beds for EEG monitoring with plans for expansion in progress. The model of staffing was similar to the previous hospitals I had visited in the US with care on the ward managed by Nurse Practitioners in collaboration with medical consultants who mostly visited on their daily rounds early in the morning. My host at Children’s was Neuroscience Clinical Nurse Specialist Carole Atkinson. The various NP’s on the ward covered General Neurology, Epilepsy, Neurosurgery and Neuro-oncology. These nurses led a multi-disciplinary meeting at 10am daily which included therapists, dietician, pharmacist, social worker and community agency representatives, to plan the care of each patient on the ward.

The neurosciences ward covered both medical and surgical aspects of epilepsy care with nursing staff educated in the care of the differing aspects of care for children with epilepsy including Ketogenic diet, of which 2 children were admitted at any one time to commence the diet. They also cared for children throughout all phases of the evaluation and epilepsy surgery process, with a structured education system that supported both new staff on commencement on the ward and continued to update the skills and knowledge of staff on an ongoing basis with the assistance and support of the permanent ward based educator.

I also met with Cheryl Cahill, Clinical Coordinator of the Epilepsy Programme and Ketogenic diet nurse for the past 19 years. A wealth of nursing experience, Cheryl leads the group of Nurse Practitioners in the outpatient department who work with the 9 Epileptologists at Boston Children’s Hospital to provide multiple daily outpatients clinics for children whose geographical boundary appears to be limited only by their insurance, personal funding and ability to travel. There are structured clinics for children or young people seeking a second opinion, VNS, Ketogenic diet and urgent review clinics for those experiencing an increase in seizure activity. Nurse Practitioner, Ann Morgan, also shared information about the phone support which the nurses provide to patients on non-clinic days. The NP receives phone calls from families and could expect to take up to 30 calls per day for various aspects of support that a family needed in caring for their child with epilepsy including requests for scripts. The team of nurses in this outpatient clinical area met before clinics each morning, as a group, to review the day’s workload and allocate the workload evenly and to check in with each other before the day starts.
I discussed transition with various staff at both Boston Children’s Hospital and BIDMC over the time I spent visiting both centres. Whilst both hospitals were fluid with the age range that they were comfortable with caring for in their facility, staff did not feel that they did transition well. There were well established links between children and adults services, and as with Johns Hopkins, there appeared no urgency or pressures to transfer young adults as evidenced by a 25 year old patient in the paediatric intensive care unit. Unfortunately I did not have the opportunity to directly ask any patients of the appropriate age range regarding recent transition experiences.

Other highlights from Boston were meeting Dr Babu Krishnamurthy to discuss the Women’s programme at BIDMC, discussions and observations of the role of the Patient Care Technician [PCT] on ward Farr 11 with Kathy Clark Hussein, EEG ward round of inpatients, discussing nurse education with Nurse Educator, Lauren Sullivan, observing nurse-led VNS clinics, discussing nursing research and collaboration projects.

Rome - Italy
Leaving the United States, I flew to Rome to the Bambino Gesù Children’s Hospital [OPBG], within the walls of the Vatican City and ‘belonging to the Holy See [Pope]’. Gesù opened in 1869 with its 4 beds, due to the generosity of the Salviati family who funded the original hospital’s foundation which then grew through the generosity of likeminded individuals until it was taken over officially by the Vatican, officially recognised in 1985 as a ‘children’s research hospital’.

My host, Immacolata Dall'Oglio, Nurse Educator and Researcher, took me on a guided tour of the hospital as part of my orientation. As space is always a premium in Italy, the hospital is no different and no space has been wasted, refurbishment of buildings is an ongoing process, rooms and wards are uncluttered and recycling is an expectation of patients and staff alike in this extremely compact but very busy tertiary care hospital.

The model of care and the model of nursing at OPBG, were the most strikingly different that I experienced in all of my travels as a fellow when comparing these to Australian models and to others in the US and UK. The model of care was a medically determined model, with the medical staff directing all nursing and allied health staff in their cares for the patient, regardless of level of experience of the nurse or allied health professional, and few nursing specific protocols or care pathways existed to support independent practice at any level. A medical director was in charge of each ward, supported by a chief physician and the nurse manager’s role on the ward was ‘to support the nurses and to do the rosters’. In my discussions with several nurses on the neurological ward, they had a vast knowledge of the cares for children with complex neurological conditions including caring for children with many conditions and situations for which the child would be in a high dependency unit in other countries, and could anticipate what was needed for the patient before an order was given. Despite this knowledge, they said they did not ever initiate discussions with the medical staff with regards to an appropriate treatment, merely highlighted the problem and waited for an order.

The ratio of nurses to patients in each of the wards, other than the neonatal and special care units, was also much higher than other countries I had visited and also Australian paediatric hospitals. A ratio of 1:9 patients was normal in most wards in OPBG. When I asked how this was managed, several details emerged. During a hospital stay for all patients, one parent or guardian must stay at all times to assist with caring for the child. The child and the guardian are not permitted to leave their hospital room at any stage during their admission unless they are going for a test e.g. x-ray, EEG. The nurses said that this was the most helpful with caring for so many patients and also for preventing cross infection. With 22 beds on the neurological ward including 2 hard-wired EEG rooms and 4 high dependency care beds on the ward, the nurses were exceptionally busy.

One of the reasons I had specifically chosen to visit the Bambino Gesù Children’s Hospital was due to my concerns around the nursing care of neonates admitted to our hospital with seizures. Neonates are children in the first month of life and for these babies, ongoing seizures which start in early infancy are
known to have a significant impact on a child’s development, usually due to the underlying aetiology. Whilst the aim is to have all children discharged from hospital as soon as possible, often babies who have seizures in infancy have difficult to control seizures, necessitating a more prolonged admission and this is a stressful time for their families. I feel that this is a critical time for nursing staff in the life of the babies and the family and wanted to visit a place where specialised services for neonates were centralised to see what we could do to improve the nursing services for families at this critical time.

Overall, what I found in Rome challenged me and my thinking of what we do for families in a way that I hadn’t expected. In the multiple neonatal and special care units [NICU] within the OPBG, the visiting hours are strictly controlled. The sickest babies in the neonatal unit have visits by parents only for 2 single hours each day. As the babies improve, the visiting hours are liberalized, but only by another 1-2 hours. All visiting hours are in the afternoons/evenings. If a baby is deemed well enough to breast feed, it is discharged to another ward, home.

When I discussed these visiting hours with Immacolata and the Nurse Manager for 2 floors of the NICU, the reasons given were that ‘the nurses and doctors had things to do for the babies in the mornings’. I questioned whether there was any concern that the parents would not bond with their baby if they had only limited time with them over many weeks, but this did not seem to be of concern. I also asked about who provided the mothers and fathers with support during this time when their baby was unwell and in hospital? This didn’t translate well but didn’t need to be answered as I returned that afternoon at the commencement of visiting hours to find multiple grandmothers, grandfathers, aunts and uncles, all restricted from being inside the ward but all peering through the windows from outside the building. Here were the supports for the mothers and fathers. Inside were parents, eager to hear about how to care for their children. They were well rested and attentive to the staff for any education they needed to receive about caring for their baby and bonding didn’t appear to be an issue.

This model of care challenged me to think about how we encourage parents to stay with their children around the clock when they are in hospital and how this effectively sleep-deprives the parent and cuts the mother or father off from their family for a number of days or longer. Whilst some babies and mothers often come from vast distances to come to our hospitals in Australia and is unavoidable, Rome has me now thinking ‘how can nurses keep mothers connected with their family and natural supports during this time’?

The Clinical Nurse Specialist role had been introduced at OPBG in the previous 18 months, with 8 currently employed in part-time capacities, and therefore the staff at the hospital were very interested in my role the Clinical Nurse Consultant [CNC] role has been well established in Australia for many years. I had the privilege of presenting information on my role as a CNC, epilepsy care in Australia and information about my Churchill Fellowship and the Churchill Trust to the multi-disciplinary research meeting at the Bambino Gesù Children’s Hospital with the assistance of an interpreter. I also met with the Director of Nursing and senior nursing staff from the hospital to further discuss the roles of nurse specialists and how the model works in Australia. Further contact will be maintained with the hospital over the coming years as their model evolves.
Research at OPBG is an integral part of nursing at all levels with an expectation that nurses will have an active involvement in research from soon after commencing at the hospital and at all levels of nursing. To facilitate this, a large multidisciplinary research group meet regularly to discuss all matters relating to research and to also educate and support staff in their research projects. Ward nurses participated in this group, but found it challenging to access other dedicated research time during work hours due to the clinical workload as previously mentioned. Despite this, they felt that research was important, with several projects currently in progress and therefore completed most of research in their own personal time. My Italian hosts have indicated a keen interest in collaborative nursing research projects between Italy and Australian sites in the future. From Rome, I have learnt that we need to develop a culture of early engagement with research in nursing.

Other highlights from Rome included a tour of the emergency department and discussions regarding the emergency management of seizures, attending an outpatient epilepsy clinic, discussion with dietician regarding historical use of Ketogenic diet, watching EEG’s in the Neuroscience department and meeting the Italian clown doctors.

**London – United Kingdom**
Great Ormond Street Hospital

From Rome I travelled to the UK to Great Ormond Street Hospital for Children [GOSH] in central London, celebrating its 160th year of service to children since opening in 1852 as the first hospital in the UK dedicated solely to caring for children with its motto ‘the child first and always’. A true tertiary service, it has no emergency department, rather all children referred to GOSH, are already under the care of a paediatrician or specialist. Entrance is past the Peter Pan statue, which symbolises the ongoing funding provided by JM Barrie since 1929 when the book rights were signed over to the hospital for the benefit of the patients.

Great Ormond Street Hospital has a long been the lead hospital in the UK for Neurology and Epilepsy services and this was evident in my observations of the functioning of the Epilepsy Programme. Each staff member’s role appeared to be well clarified and the routine was well established. There had been a very recent move of the inpatient ward and I arrived at the start of a patient ward round. Consideration had been given to including a generous size meeting room and technology on the new ward to assist with presentation of patient information prior to ward rounds, and for other meetings and education, and this proved helpful as the size of the ward-round group who met was considerable.

The hard-wired rooms on the new ward were similar to others in previous hospitals and appeared spacious and comfortable for patient and family with sufficient room for nursing staff to access the patient safely. Wall mounted computers and monitoring equipment assisted with creating more floor space. The nursing staff on the ward were from a combination of 2 wards prior to the move to this ‘Koala Ward’, being from the neurological and the neurosurgical ward respectively, and had undergone a period structured education prior to the merge. This education had greatly assisted with the merge of the wards 2 months prior and, in conjunction with some astute rostering practices, had ensured that most aspects of care were seamless. Well established and documented care paths for patients also assisted in this transition phase. Over the course of my visit to GOSH, I had further in-depth discussions with my host, Hannah Chaffe, and Nurse Practitioner for CNS Tumours, Sarah Wallington, regarding these processes, with the view to further planning for the opening of the Queensland Children’s Hospital in late 2014.
The epilepsy service at GOSH is provided by a number of Neurologists and Epileptologists and there are several Clinical Nurse Specialists [CNS] and also a Nurse Practitioner within the team. Each nurse has a defined area/s of expertise and clinical interest, but all provide support for one another patients when the need arises. Both the CNS and NP devote time during their day to supporting the inpatient and outpatient clinic areas as well as support for patients via the telephone and email.

Ketogenic diet at GOSH is commenced as an outpatient, which is in contrast to the US or Australia, unless the child is under 1 year of age, therefore Hannah provides intense support via telephone and email to the families, especially in the early weeks of the diet as the ratios are being adjusted and the most intense learning phase is taking place. GOSH currently has ~30 patients on Ketogenic diet and there are 2 clinics per month to support this programme. A further 2 clinics per month with Nurse Practitioner Nicky Barnes supports the patients with Vagus Nerve Stimulator devices, of which there are currently 30 in situ. Nicky attends theses clinics to manage all aspects of the patient care and adjustment of device settings.

Discussions regarding Nurse Specialists and the Nurse Practitioners in the UK revealed some similarities between Australian nurses and some differences in both the education and the provision of services. Most markedly was for the Nurse Practitioner position whereby the nurse is employed in the position before they commence their NP course. The hospital then sponsors the nurse to complete 2 NP modules each year, which can take up to 5 years to complete, with the nurse becoming more autonomous as more modules are completed. In Australia, the course is completed prior to the NP being employed in the role and generally, the course would take less than 2 years to complete.

Leading on from these discussions, I was offered the opportunity to attend a meeting to discuss the proposed Masters Programme for Charge Nurses with the Assistant Chief Nurse of Great Ormond Street Hospital, Ms Chris Caldwell. This meeting involved several Chief Nurses from local hospitals and Heads of Schools from local Universities who were planning to conduct the programme as part of a UCL Partners project, an academic health science partnership. The meeting discussed recruiting 15 candidates from north and north-west London, and how the Masters Programme would be conducted for the foundation group. The recognition of the necessity and importance for academic qualification for nurses in the Charge Nurse role was refreshing and it was a privilege to be offered the opportunity to be included in discussions regarding aspects of the proposals for the academic programme. The importance of education for nurses, is certainly relayed from the Assistant Chief Nurse, both formally and informally to other nurses in the hospital with positive outcomes for both patient and staff.

Other highlights from Great Ormond Street Hospital were attending the Sturge Weber clinic, attending inservice for Buccolam medication and attending epilepsy surgical meeting.
Edinburgh – United Kingdom  
Royal Hospital for Sick Children

The last stay of my fellowship came via a kind invitation to add an additional hospital to my tour. It was a pleasure to take the train from London to Edinburgh to the Royal Hospital for Sick Kids, commonly shortened to ‘Sick Kids’. Whilst the weather was the coldest I had encountered, the welcome was exceedingly warm. Sick Kids has been home to medical and nursing care since 1860, when it very opened without fanfare with 12 inpatient beds, 8 convalescent beds, dispensary and an outpatient department. As with other hospitals of its vintage, its services have grown and become established over time to where they are today.

Although the hospital may look small in size, and is relocating with expansion to the Little France site in the future, there is a noteworthy amount of epilepsy care that is managed from this the site. Recent changes in the model of care throughout the United Kingdom will also see an increase in workload as epilepsy surgery, previously performed exclusively at GOSH, will be de-centralised to several regional hospitals, of which Sick Kids is one such hospital, meaning that children in this local region will no longer have to travel further from their homes for specialist epilepsy surgery. Sick Kids already receive children during the recovery phase following surgery and were enthusiastic about the positive changes that this would mean for patients and their families.

There are currently 6 Neurologists working at Sick Kids and 3 specialist Nurses covering the inpatient unit, outpatient department and several outreach clinics. The inpatient unit is a 12 bed ward with 2 hard-wired EEG rooms for video monitoring with an additional 2 outpatient EEG testing rooms and clinic rooms adjacent to this ward, with further outpatient clinic rooms in the outpatient department. It was anticipated 12 children per year would be having surgery at the hospital when the model changed over.

Each of the 3 specialist nurses covered different aspects of epilepsy care including Ketogenic diet, VNS, emergency management etc. but also covered for each other when needed. Celia Brand, my main contact person prior to the visit, is an Epilepsy Clinical Nurse Consultant, the equivalent of an Australian NP, and
the senior nurse in this group, supporting and mentoring the other Specialist Nurses. Celia has her own nurse-led clinics and while the other nurses attended clinics with one of the neurologists, their model of care also included time for seeing patients independently. All nurses had added phone consultations with patients and their families to support them in various aspects of their epilepsy care. If the specialist nurses made medication changes, processes were in place to notify the child’s GP and/or Paediatrician at the end of each month via brief proforma letters. These small communication tools would prove beneficial for a condition whereby medication changes are often made regularly if the child has complex epilepsy and where care is shared between several treating professionals.

There were challenges being faced and most were associated with lack of funding throughout the National Health Service [NHS] including funding having ceased for ward nursing educators. Despite their challenges, the Royal Hospital for Sick Kids made a significant collaborative contribution to the care of children and young people with epilepsy each year in addition to providing teaching, training and support for medical and nursing services in a variety of settings including outreach services, which I had the pleasure to attend during my brief stay. Nursing education was still a priority and modifications had been made to accommodate the loss of the ward Educator.

Other highlights from Edinburgh included meeting the Neuropsychologist and attending epilepsy clinics at Sick Kids Hospital with Dr Ailsa McLellan and Dr Richard Chin.

Summary

Comprehensive Epilepsy Programmes are viewed as the leads in Epilepsy care for children within their region and as such, being within tertiary facilities also shoulders a responsibility for ongoing teaching and research in the area of Epilepsy. Each of the hospitals that I had the privilege to visit had a well established service for children and young people with epilepsy. Each centre had a stronger emphasis on specific aspects of epilepsy care, which had developed over a number of years, perhaps in response to a particular need identified, due to available funding or due to the expertise or strength that a member of the team brought to the Comprehensive Epilepsy Programme at the time. Each centre also identified areas in which they would like to further enhance their services, offering encouragement for the advancement of quality care and outcomes for patients.

The NICE Guideline and SIGN document, which are often cited as guidances for the care of children with seizures and epilepsy, although labelled as guidelines, are quite prescriptive in their instructions with what they consider as best practice for service models for children and adults. Limited work has been completed on how services in Australia have been modelled or are to be modelled and as stated earlier, funding for services has been the jurisdiction of each state.

Whilst Australia has adopted much of the NICE guidelines for medical aspects of epilepsy care, access to epilepsy specialist nurses for all patients with epilepsy is somewhat limited for a variety of reasons. Perhaps this is a lack of personnel, lack of a defined face to epilepsy nursing as a specialty as in the UK and US, possibly geographical considerations or something more evolutionary that it is yet to occur. Regardless of the reasons for how things are, there is always the ability to improve services for children and young people with epilepsy. Some improvements may take a number of years to become established to the levels of the overseas centres I visited but by placing the patient and their family at the centre of our focus, we are able to challenge ourselves, think creatively and remove barriers in order to improve our services.
It is therefore my recommendation that the following changes are made to improve the care for children and young people with epilepsy as provided by the nurses of Australia:

- An Australia-wide competency-based education programme for ward-based nursing staff
- Nurse Practitioner role is further developed in Australia
- Strengthening of the voice of Epilepsy specialty nursing throughout Australia
- Nurse-led clinics are part of all Australian Comprehensive Epilepsy Programmes
- Australian Epilepsy Nurses Special Interest Group (ENSIGA), collaboratively with the American Nurses group, develops a formalised education qualification for Epilepsy Specialist Nurses
- Upgrading the medication systems currently in use in tertiary paediatric hospitals

I was introduced or introduced myself to over 500 people during the course of my travels and had meaningful conversations about my project and the work of the Churchill Trust with over 100. I have gained a huge insight into how nurses care for children and young people with epilepsy and their families in different centres during my time abroad. I have also been privileged to be able to share information about the services provided in Queensland by my own team and information about health care in Australia.

It has been the greatest honour to be able to visit so many places providing excellence in epilepsy care for children and young people and I have so much to share and encourage in excellence for the care of children and young people with epilepsy in Australia. Dissemination of my work will continue as planned in the executive summary of the document.

My journey will continue as I seek opportunities to advocate for best practice in epilepsy nursing care and actively encourage others to apply for a unique learning experience through the Churchill Trust.

In closing, I humbly wish to again thank the generosity of Mr Bob and the late June Prickett for making this journey a reality.

Reference List
Additional information
1. VNS Therapy:  
2. Ketogenic Diet:  
   http://www.epilepsyqueensland.com.au/site/content/the-ketogenic-diet
3. Epilepsy Surgery:  