The Winston Churchill Memorial Trust of Australia

Report by
ISABEL BAKER
2009 Churchill Fellow

The Dr Dorothea Sandars Churchill Fellowship
to investigate innovation in physiotherapy for
children with acquired spinal cord injury

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Signed: Dated: 22/02/2010
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Introduction

Spinal cord injury (SCI) in childhood is relatively rare but tragic. This catastrophic condition is complex and lifelong. Effects of paralysis, sensory loss and change to automatic bodily functions can be devastating on the developing child and many of the manifestations are unique to this population. Children’s needs and skill requirements, unlike those in adults with spinal cord injury, change constantly with growth, maturation and evolving roles in society.

Increasingly, scientific evidence is shedding light on strategies to manage issues specific to paediatric SCI. In addition, a paradigm shift is occurring in the way people with SCI are in general training their bodies. Intense activity based programs are targeting areas below the level of injury more than ever before. It is incumbent on us as professionals to investigate applications to children.

My profession is Senior Physiotherapist on the New South Wales (NSW) Paediatric Spinal Outreach Service (a joint project of Northcott Disability Services and the Spinecare Foundation, supported by NSW Health). My position is unique, in that no other physiotherapist in Australia treats only children with SCI. The Churchill Fellowship has enabled me to pursue a long term desire to improve the health and lifestyle of those SCI-affected children with whom I work in Australia.

As a Churchill Fellow, I travelled to Italy, UK, Canada and US, to interact with and learn from internationally recognised professionals at conferences and in their working environs. I have visited the most highly regarded and advanced clinical spinal and research facilities with innovative intensive programs, specialist equipment and dedicated rehabilitation arrangements for children. As no equivalent services are available in Australia, nor do dedicated facilities exist, it was an exhilarating and deeply inspirational experience for me to see firsthand how these facilities operate. Research in the area of childhood SCI is minimal in Australia and no research in allied health is carried out. To date, these activities appear not to have been given priority, perhaps because of the low numbers in Australia or insufficient history of service infrastructure.

I organised the travelling component of the Churchill Fellowship to attend two important and highly regarded international conferences. The first conference, the Annual Scientific Meeting of the International Spinal Cord Society (ISCoS, Florence), for the first time, workshops and lectures were devoted to treatment of children. The other, the Howard H. Steel Conference on Paediatric Spinal Cord Injury and Dysfunction (Orlando), occurs only every 3 years and is the only one of its scale dedicated to paediatric spinal cord dysfunction. Given the honour and opportunity, I presented a paper at this conference on the model of service and strategies applied to children with SCI in NSW, Australia. On request, at a number of venues in the UK, Canada and US, I gave other presentations which expanded on the work of the Paediatric Spinal Outreach Team. These presentations were very well received and served as a valuable opportunity to gain feedback from the international community.
The ensuing report presents details of my interactions, observations and learning experiences during my study tour. It encompasses knowledge, tools and practices that are either innovative in the field or not currently practised in Australia. This work necessarily has an emphasis on the young, those injured prior to skeletal maturity. While such information may be pertinent to physiotherapy practice many aspects are specialised, relevant and are directed to young people and families affected by spinal cord injury, health and medical professionals interested in this area, funding bodies and policy makers.
Acknowledgements

As a sponsored Churchill Fellow, I gratefully acknowledge the late Dr Dorothea Sandars, in whose name I accepted this prestigious award. I am able to pursue this important work because of her commitment and generosity to the mission of the Trust. I am also deeply grateful for the continued interest in my work of Irene Lee, her lifelong friend and I sincerely enjoy our correspondence.

I wholeheartedly thank all representatives of the Winston Churchill Memorial Trust. This extraordinary opportunity is made possible because of your dedication, utmost professionalism and generosity of time and spirit. Thank you for recognising my passion and having faith in my potential.

I thank my employers, Northcott Disability Services and Vision Australia for their support of this valuable Fellowship experience with its significant responsibility. I am especially grateful to my colleagues of the NSW Paediatric Spinal Outreach Service for sharing my commitment to continuous improvement, knowledge growth and skills development to serve better the children and families affected by spinal cord injury.

My deep appreciation goes to all the professionals who hosted my visits, gave generously of their time and inspired me with their critical thinking and expert skills. Thank you for embracing this exchange and truly making me feel part of the ‘family’. I am impressed by your passion, dedication and energy. Acknowledging your distinct contributions to this field for many years, I look forward to further professional exchanges and collaborations.

Thank you to all the young characters and families whom I met on my travels and also my clients and families at home in Australia. Thank you for sharing your lives and those times which are often sensitive and challenging. I do not take for granted how precious this is and never cease to learn and be inspired by you.

Finally, I thank my dear family and friends for your enduring love, support and unending encouragement, especially throughout my Fellowship experience. Like events in the life of Sir Winston himself, the great are often entwined with adversity. Sadly I lost my grandmother while on my study tour. I thank my family for strength and determination that prevailed for all of us, ensuring that this unique and once in a lifetime opportunity was optimised.
Executive Summary

Fellow details
Ms Isabel Baker, Paediatric Physiotherapist
Northcott Disability Services & Vision Australia
PO Box 107 Beecroft NSW 2119
Isabel.paedsphysio@gmail.com

Fellowship objective
To investigate innovation
in physiotherapy
for children with
acquired spinal cord injury

Major lessons
Spinal cord injury in childhood is unique in its presentation and manifestation in the growing body. It can impact on all aspects of development. Dedicated programs and rehabilitation facilities, such as Shriners and Stoke Mandeville Hospitals and Kennedy Krieger Institute, offer expert knowledge, skills, specialised equipment, surgical procedures and opportunity for peer interaction of affected children and families. Clinical outcomes there are researched to advance knowledge and care.

- A paradigm of activity-based rehabilitation and its science is influencing practice. Children may be great beneficiaries of advancements in this area, in mitigating the devastating effects of spinal cord injury on the growing body and harnessing potential in the immature nervous system. Evidence substantiates positive health benefits but neurological recovery is variable and nominal. New knowledge and technology is guiding anticipatory care and preventative strategies.
- Strategies to optimise community integration and to support all areas of child development are paramount to quality of life.

Highlights
- Being invigorated at two outstanding international conferences by a considerable array of state-of-the-art scientific and clinical advancement in paediatric spinal cord injury and appreciating interaction with inspiring, creative and highly respected international colleagues;
- Experiencing firsthand the philanthropic Shriners network of world leading and exemplary staff;
- Meeting Sir Hans Frankel at the ISCoS Conference opening ceremony in Palazzo Vecchio, Florence.

Recommendations & Implementation into Australia
- Adequately resourced specialist paediatric services should provide activity based therapies, education to families and local service providers, specialist equipment and spinal specific group programs.
- Acquired knowledge and skills will advance the Northcott Paediatric Spinal Outreach Service in NSW. Proposed group programs will have multiple benefits. Web based strategies will be important.
- Children with acquired spinal cord injury should be included in national data collection and research initiatives. Low incidence and heterogeneous presentation may warrant international collaboration.
- Selected tertiary paediatric facilities should be identified as centres of specialisation and motion analysis facilities expand programs beyond gait and to a wider paediatric population.
- Rehabilitation of complex and chronic paediatric conditions should be conducted by applying life skill oriented and goal directed philosophies, in wellness environments. Dedicated children’s rehabilitation centres and development of programs attached to existing services are desirable.
### Fellowship Itinerary

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<thead>
<tr>
<th>DATES</th>
<th>LOCATION</th>
<th>FACILITY</th>
<th>KEY CONTACTS</th>
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<tbody>
<tr>
<td>19th October &amp; 30th-</td>
<td>Salisbury, Wiltshire, UK</td>
<td>National Clinical FES (Functional Electrical Stimulation) Centre, Salisbury District Hospital</td>
<td>Ingrid Wilkinson, PT Duncan Wood, PhD</td>
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<td>31st October</td>
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<tr>
<td>21st – 24th October</td>
<td>Florence, Tuscany, Italy</td>
<td>International Spinal Cord Society (ISCOS) 48th Annual Scientific Meeting</td>
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<td>26th – 29th October</td>
<td>Aylesbury, Buckinghamshire, UK</td>
<td>Stoke Mandeville Hospital, National Spinal Injury Centre (NSIC)</td>
<td>Kirsten Hart, PT Ebba Bergström, PT</td>
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<td>5th – 11th November</td>
<td>Vancouver, British Columbia, Canada</td>
<td>British Columbia Children’s Hospital</td>
<td>Bonita Sawatsky,</td>
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<td>GF Strong (Adult Spinal Rehabilitation)</td>
<td>A/Prof</td>
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<td>Sunny Hill Children’s Health Care Centre (Children’s rehabilitation)</td>
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<td>International Collaboration on Repair Discoveries (ICORD), Blusson Spinal Cord Centre</td>
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<td>12th – 13th November</td>
<td>Saint Paul, Minnesota, US</td>
<td>Gillette Children’s Specialty Healthcare</td>
<td>Kath Roske, PT</td>
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<td>14th – 18th November</td>
<td>Chicago, Illinois, US</td>
<td>Easter Seals Disability Services – (affiliated with Ability First Australia &amp; Northcott Disability Services)</td>
<td>Ellen Harrington-Kane, MS Lawrence Vogal, MD</td>
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<td>Shriner's Hospitals for Children Chicago</td>
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<td>Rehabilitation Institute of Chicago</td>
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<td>27th November – 1st December</td>
<td>Baltimore, Maryland, US</td>
<td>Kennedy Krieger Institute (KKI)</td>
<td>Karen Good, PT</td>
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<td>7th – 8th December</td>
<td>Miami, Florida, US</td>
<td>Miami Project to Cure Paralysis</td>
<td>Kathleen Manella, PT Gillian Hotz, A/Prof</td>
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<td>Ryder Trauma Center, Holtz Children’s Hospital &amp; Jackson Memorial Hospital</td>
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<td>Miami Physical Therapy Associates, Inc (Private Practice)</td>
<td>Miriam Guanche, PT Marlene Burt, PT</td>
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<td>Miami Children’s Hospital</td>
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<tr>
<td>9th December</td>
<td>Downey, Los Angeles, US</td>
<td>Rancho Los Amigos National Rehabilitation Center</td>
<td>Jan Furumasu, PT</td>
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<tr>
<td>11th December</td>
<td>Carlsbad, Los Angeles, US</td>
<td>Project Walk</td>
<td>Eric Harness</td>
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Databases, classification & measurement

Data collection
In Australia, little is recorded about the epidemiology of spinal cord injury acquired in childhood. While the Australian Spinal Cord Injury Register (ASCIR) has taken the initiative to collate and publish data from specialist spinal units, such information is incomplete and needs to be considerably expanded.

From this work, it is estimated that, in Australia, the age-adjusted incidence of childhood spinal cord injury (SCI) is 14.9 cases per million (Cripps, 2009). Cases under the age of 15 are often omitted from analysis due to a paucity of data. In Europe, the incidence of paediatric SCI is estimated to range between 0.9 – 27 per million children per year (Augutis et al., 2006; Augutis & Levi, 2003a) and, in the USA, 19.9 per million children per year (Vitale et al., 2006).

Children in Australia, with traumatic and non-traumatic SCI tend to be managed in a tertiary teaching Children’s hospital. Many others with non-traumatic injuries may be managed elsewhere, as is the case in adults (New, 2006).

Spinal cord injury is not a reportable condition in Australia or in the countries visited on my study tour. Nonetheless, several of the facilities visited have been collating data on SCI for decades. I learnt of an epidemiological and clinical data pool commenced in the 1970s from my host, Kirsten Hart, physiotherapist (PT) at Stoke Mandeville Hospital, UK. This pool contains information on thousands of children, such as anthropometric measures and medical photography. From this database, Ebba Bergström, research physiotherapist, with whom I also conferred, completed her Masters of Philosophy on “Childhood Spinal Cord Lesion: Its effect on skeletal development, growth and lung function – A retrospective study” (Bergström, 1994), to offer insight and management recommendations that are relevant today (Bergström et al., 2003; Bergström et al., 1999).

During an enlightening meeting with Lori Rutter, Nurse and SCI program coordinator at Shriners Philadelphia, I was informed of the National Shriners Spinal Cord Injury database (Shrine Database) of patients of the three Shriners Children’s Hospitals that specialise in spinal cord injury (Sacramento, Chicago, Philadelphia). At Head office in Tampa, Florida, information is stored on injury, education attendance (e.g. return to school post injury and type of education) and a range of clinical markers (e.g. bowel and bladder management). Follow-up questionnaires on large samples are conducted annually to determine effectiveness of intervention and to gain insight into this population. The earliest data commence in the 1970s when the Shrine network expanded its mission to treating children with SCI (McCollough, 2000). Recent publications convey trends from analysis of tens of thousands of patients (e.g. (Shavelle et al., 2007). At the 2009 ISCoS conference, Dr DeVivo expressed the view that a limitation in this database is that it is not population based and therefore that estimates of incidence and prevalence cannot be made. In published work with Dr Vogel, data from both the Shrine Database and the American National SCI Statistical Centre provide valuable insights into epidemiology of childhood SCI in the US (DeVivo & Vogel, 2004).
At the scheduled meeting of Members of the American Spinal Injury Society (ASIA) and experts in the field in Copenhagen, May, 2010, Associate Professor Mary Jane Mulcahey from Shriners Philadelphia and the panel aim to identify the most critical variables for a paediatric International Data Set. Current ASIA International Data Sets are available at http://www.asia-spinalinjury.org/bulletinBoard/dataset.php.

During my visit to the Rick Hansen Institute (formerly SCI Solutions Network, Blusson Spinal Cord Centre, ICORD), Dr Chris McBride, Director of the Translational Research Program, summarised the aims and outcomes of the Institute. Of relevance here is the development of a novel technology platform for data collection by the new National SCI Registry (http://rickhansenregistry.org). Currently the data collection is limited to traumatically injured adults and when available, may have broader relevance for Australia (e.g. children and non-traumatic injuries). The recently signed Memorandum of Understanding between Australia New Zealand Spinal Cord Injury Network (ANZSCIN) and Rick Hanson Institute in Canada should be a vehicle for collaboration.

The ASIA Standards examination & WeeSTeP
At both ISCoS and Howard Steel 2009 conferences, the following key points, based on a large scale, high quality reliability trial (Chafetz et al., 2009), were made in relation to children:

- Motor and sensory examinations have utility for children as young as 6 years, with good to high inter-rater reliability.
- The ASIA exam should be reserved until a child reaches age 6 but the results be interpreted with caution until the age of at least 8. A clinical estimate may be applied for children younger than 5 years. At age 5 a tester may attempt the exam within professional judgement.
- The inter-rater reliability of the anorectal part of the exam is poor in children. The validity of this part of the exam is questionable across all age groups. Results should be interpreted with caution.
- Cognition should be tested (informally) prior to engaging children in the exam. Language used should be age appropriate (e.g. replace ‘sharp’ with ‘pointy’ during the sensory exam).
- Children injured prior to being toilet trained may not understand instruction for the anorectal exam. Modifications to instruction should be made accordingly.
- The examiner must make provisions for presence of scoliosis, pelvic obliquity and hip dysplasia, especially when testing dermatomes.

During my stay at Shriners Philadelphia, I completed the newly developed online training module ‘WeeSTeP’, which was pioneered by talented staff of the Shriners network and the American Spinal Injury Association (ASIA). ‘WeeSTeP’ addresses considerations specific to children in the conduct of the ASIA Standards exam and incorporates the latest research evidence of its use in children. It is available at http://www.asialearningcenter.com with purchase of InSTeP (six module course for conducting the ASIA Standards exam). The simple yet comprehensive instructions are supported by videos of clinical scenarios.
Diffusion Tensor Imaging (DTI)

DTI is a relatively new Medical Resonance Imaging (MRI) technique currently used in brain pathology. Researchers at Temple University and Shriners Hospital Philadelphia are working to ascertain whether DTI can be an adjunct to the ASIA standards examination. Typically in children, both in Australia and elsewhere, current MRI techniques provide a neurological classification to children. Research findings substantiate a correlation with the level (Samdani et al., 2009). Techniques to ascertain the severity of injury are limited.

I was accompanied to the MRI scanner by Louise Hunter, research physical therapist (PT) at Shriners Philadelphia, Dr Nadia Barakat of Temple University and their young SCI subjects. The principal investigator of this work is Dr Feroze Mohamad of Temple University. Key points learned about this technique are:

- DTI is performed in a regular MRI scanner and takes 6 minutes more than normal scans. Two main values are extracted, namely Fractional Anisotrophy (FA) and Diffusivity (D), indicators of myelination and tissue microstructural organisation.
- Current investigations are restricted to cervical spine, as movement from heart beat and respiration cause imaging of the thoracic spine to be noisy.
- Provisional studies using this technique in children with and without spinal cord damage have demonstrated feasibility and reproducible differences in FA and D values between these two groups (Samdani, 2009).
- Further study is required to ascertain whether DTI is a viable method of measuring impairment in children with SCI. In children under 6, where the ASIA exam is known to be unreliable, DTI may become the gold standard for classification of the injury site and severity, failing development of valid and reliable clinical diagnostic tools for this population.

Motion Analysis Laboratories

Traditionally, 3D ‘gait laboratories’ have focused their resources on analysis of walking patterns in children with cerebral palsy. A gait laboratory often houses a sophisticated series of semi-infra red cameras, digital video cameras, acquisition and analysis computer software, floor mounted force plates and electromyographic (EMG) equipment.

In recognition of wider applications, many of the laboratories visited have renamed this part of their facility ‘motion analysis laboratory’ and have extended biomechanical observations to the upper limbs and trunk. Further, children with SCI, who were once seldom candidates for gait analysis, are being monitored in this setting.

Staff at Shriners Hospital Chicago are pioneering the use of 3D motion analysis for children with SCI. In a stimulating visit to their lab, I heard Dr Larry Vogel, Chief of Pediatrics and Joesph Krzak, senior motion analysis laboratory PT, explain how motion data are being used to optimise positioning, set-up and propulsion strategies for children who use manual
wheelchairs. The aim is to reduce incidence of musculoskeletal dysfunction (e.g. neck, shoulder and wrist pain) while improving propulsion efficiency. Kinematic, kinetic and EMG data from newly developed software package “Bodybuilder” (Marquette University/Medical College of Wisconsin) may be further enhanced by amalgamation with force data from the paediatric SmartWheel®, when available (see below).

In this setting, gait analysis of ambulatory children with SCI has rendered more objective the effectiveness of: (1) innovative but costly interventions (such as BWSTT and Lokomat training – see ‘Life in motion – activity based rehabilitation’), (2) traditional SCI interventions such as bracing and (3) novel applications of orthopaedic surgery.

At Shriners Hospital Philadelphia, David Hutchinson, physical therapist and Director of the Motion Analysis Laboratory (MAL), introduced me to the applications of motion analysis for clinical evaluation and research in (1) upper limb tendon transfers and (2) orthotic prescription for children with SCI. His work on comparison of conventional orthotics with the more novel stance control orthotics (SCO) is discussed in this document: ‘Achieving Upright Mobility’.

The motion analysis ‘arena’ at the newly located ICORD, in Blusson Spinal Cord Centre contains an impressive array of moveable floor tiles, many of which are force plates. The plates may be arranged in a large circular shape for analysis of an array or gross motor or wheelchair skills as well as in the traditional ‘run-way’ arrangement. Several of the cameras, mounted on steel frames, are mobile and EMG tools are wireless.

Paediatric SmartWheel™
The SmartWheel™ is a sophisticated device built into a wheelchair wheel and offers precise information about wheelchair propulsion. It measures push force, frequency, length, smoothness, speed and duration of hand contact with the rim. These outputs are processed to deliver computer generated reports and graphs, which enable a qualified professional (e.g. a PT) to assess and review wheelchair push performance. They may also be used to:

- Identify if a wheelchair user has appropriate propulsion strategy to function in society (e.g. sufficient speed to cross the road with traffic lights). A rehabilitation strategy may then be devised for meeting community needs and reassessment performed subsequently.
- Modify wheelchair set-up to minimise forces and thereby reduce risk or severity of upper limb dysfunction and pain.
- Provide feedback to the wheelchair user to optimise motor learning of the most efficient propulsion strategy (once again to minimise upper limb pain and improve function).
- Assist in decision making about the most appropriate form of wheeled mobility (e.g. ultra-light manual chair, power chair) and justify choices to funding providers.
- Devise strengthening and conditioning programs to improve propulsion capacity.
Until recently, the SmartWheel™ was available in one adult sized rim only (24 inch). In mid 2009, its creator, Three Rivers Holdings (www.3rivers.com), released the much awaited 22 inch paediatric size (in addition to 25 and 26 inch. Little information is available about propulsion strategies of children.

The SmartWheel™ user group, established in 2004, created a standard clinical protocol which was utilised to propagate a database of normalised reference values for adults. With the availability of the paediatric size, Christin Krey, PT at Shriners Philadelphia, joined the user group and is generating reference values for children. She demonstrated the utility of the SmartWheel™ in a clinical session with a 13 year old. Three repeated trials over a 10 meter distance, with the SmartWheel™ alternatively placed on the left and right sides, enabled quantitative feedback to the subject about propulsion technique. By the end of the training session, a significant reduction in force output was achieved for a given distance. Further, the propulsion strategy was more closely associated with less long term upper limb pain and dysfunction.

Associate Professor Bonita (Bonnie) Sawatzky, my host at ICORD, will acquire a paediatric sized SmartWheel™ in the near future. She is hosting the annual SmartWheel User Group meeting in Vancouver, May 2010 and is a key contributor to evaluation of manual wheelchair propulsion within this framework (Cowan et al., 2008).

**Other clinical tools**

On my study tour, 3 unusual clinical tools, alongside the familiar ones were encountered. These are specifically employed for children with SCI but may also be of value in other clinical populations (e.g. spina bifida, cerebral palsy).

**Arm girth: an anthropometric measure**

I observed the anthropometric measure of arm girth at Stoke Mandeville Hospital, recorded there by therapists for more than 30 years. My host, senior physiotherapist (PT) Kirsten Hart, demonstrated the Harpenden Anthropometer to measure the longitudinal distance between the tips of the third digit on either hand. The child is positioned supine with arms stretched out and shoulders at 90° abduction.

Combined with other anthropometric data this measure may be used to predict the final ability of a child with cervical SCI injury to effect a transfer (Bergström et al., 1985), to predict normal lung function (Bergström et al., 2003) and to estimate expected height if fully weight bearing or to detect periods of rapid growth.

**Medical photography of the growing spine**

In a fascinating discussion with Dr Ebba Bergström, research PT at Stoke Mandeville Hospital, I learned of a long standing medical photography technique that supplements traditional Xray imaging for surveillance of scoliosis. The physiotherapist applies a series of adhesive dots to the bony prominences of the child (spinous processes, posterior iliac spine, sacrum) after which posterior and lateral photographic views are taken. Curve progression is monitored in conjunction with Cobb angle Xray measurements at regular intervals.
Finding motor points for NMES – the water test

Surface electrodes for neuromuscular electrical stimulation (NMES) are often applied to the motor points of muscles, generally determined from anatomical knowledge. In children, small limbs and muscles, as well as an immature neuromuscular system may pose a challenge for the optimal placement of electrodes. A ‘water test’ has been adapted by the team at Kennedy Krieger Institute for finding motor points in children. This test has not been validated or investigated for reliability but may prove useful in the clinical setting.

Steps for the “water test” for one channel of a NMES unit with an active and an indifferent electrode are as follows:

1. Apply the indifferent electrode on the child’s body part intended to be stimulated.
2. Apply the active electrode to the palm of the tester’s hand. Dip the finger of that same hand in water.
3. Run the wet finger of the tester across areas in the vicinity of expected motor point (for the muscle intended to be stimulated).
4. Mark the point on the child’s body part where the tester has sensation of the greatest electrical activity and apply a fresh (single patient use) active electrode.
5. Proceed with NMES.

The section entitled “Life in motion – activity based rehabilitation” contains information on clinical applications of NMES.

Prevention, proactive emergency care & piglets

Innovative education strategies have been designed and implemented by allied health professionals involved in the care of children and youths with acquired SCI in an effort to reduce the numbers presenting with catastrophic injuries. Use of protective devices during high risk activity is another method of mitigating injury risk.

When spinal trauma is suspected in a child, the mechanism of injury, emergency management strategies and a unique presentation need to be considered within the context of the immature body.

In this section strategies for prevention are discussed and information relevant to emergency care briefly introduced. A newly developed large animal model of the infant is also presented for application in experimental cell biology trials (e.g. stem cells).

Education

“ThinkFirst” is a national injury prevention foundation of the US. It was established in 1986 to offer education to those most vulnerable to traumatic injury such as brain and spinal injury. The model is based on chapters adopted by different organisations around the country. Shriners Philadelphia adopted a chapter of “ThinkFirst” in 1998 in recognition of responsibility to spread the word about prevention
while still providing specialist rehabilitation services to children with acquired spinal cord injury. Purchase of a registered chapter provides health professionals with the impetus, tools and support to offer a research-validated, multi-level education program to young people. My host, Christina Calhoun, Research PT, described her involvement in the Shrine’s chapter, with novel approaches to delivering the prevention message in schools at assembly time. The team is currently developing this initiative further and I was privileged to participate in one of the planning meetings. Information about the national program is available at http://www.thinkfirst.org.

The YiPES (Youth Injury Prevention Education at Shepherd) is a recently developed program (2009) that embraces online social networking as a vehicle to deliver injury prevention messages to the young. Web sites such as Facebook®, Youtube® and Twitter® show videos of adolescents spreading a health promotion message. These adolescents, catastrophically injured while engaging in risk taking behaviour, echo messages “don’t do what I did” while raising awareness about spinal cord injury. The Shepherd Centre specialises in spinal cord and brain injury research and rehabilitation and offers a specialised adolescent program. I was exposed to this work at ISCoS and liaised with Cathi Dugger, PT, who is involved in this initiative. The impetus for this program is that health promotion messages are more powerful and effective when coming from young people themselves http://www.facebook.com/pages/YiPES-Youth-and-Injury-Prevention-Education-at-Shepherd/39671282161.

In NSW, a project has been completed to characterise the spectrum of traumatic spinal injuries in children (Bilston & Brown, 2007). This may be utilised for effective preventative campaigns in Australia.

**Protective Devices**

A paucity of equipment to protect and prevent injury to spinal column contrasts with the plethora of protective head gear that is at least partially responsible for a significant reduction in traumatic brain injury.

From a meeting with Claire Jones, PhD Candidate in the Orthopaedic and Injury Biomechanics Laboratory (Departments of Mechanical Engineering and Orthopaedics, ICORD, University of British Columbia) I gained great insight into the significant work required to design a helmet that will mitigate risk of cervical spinal cord injury. In a team lead by Dr Peter Cripton, human cadaver necks, surrogate neck-forms, finite element and dynamic computational modelling are employed to deepen understanding of biomechanical aspects of the spinal column and cord injury. Development of the helmet concept on adult models is in its early stages. The ultimate aim of the helmet is to minimise load on the neck during an impact, where it is understood that when wearing a regular helmet the cervical spinal cord may become a “trapped straight column load between the head and the torso” rendering it susceptible to injury. The helmet has been named PRO-NECK-TOR™. Information is available at http://www.uilo.ubc.ca/tech_ops/06-092%20Tech%n20Op.pdf.

An alternative prophylactic device to repel cervical spinal cord injury is a form of neck collar. At ISCoS, I learnt of the Leatt Brace™ (http://www.leatt-brace.com), which was the first commercial device to offer neck protection whilst participating in high risk sports such as motocross (de Jongh, 2009). The device
functions on a principle called "Alternative Loadpath Technology™", whereby the device takes on the load transferred from the helmet and directs it away from the cervical spine into the adjacent upper torso structures in a controlled decelerated fashion” (courtesy of Cornel de Jongh, Biomedical Engineer, via email correspondence). A size suitable for children is available and a junior specific model is being developed. Consideration for the biomechanical differences in the head and neck of a child may be found in the work by (Arbogast et al., 2003).

**Emergency Care**

A number of key points discussed at the two attended 2009 conferences are pertinent for paramedic and emergency medical staff encountering a child suspected a sustaining a spinal cord injury:

- To accommodate the relatively large head, young children should be transported supine on a board with a head hole. Otherwise towels or blankets should be used to elevate the body minus the head (Mulcahey, 2009b based on Herzenberg et al., 1989).
- Delayed onset of symptoms should be considered (Vogel, 2009).
- With the advent of advancement in medical resonance techniques, the term SCIWORA (spinal cord injury without radiological abnormality) is becoming obsolete. Initial MRI however may not detect SCI damage (Vogel, 2009).
- Lap-belt injuries remain a common cause of SCI in small children involved in road accidents. Diagnosis can be challenging due to complex injuries. Cord injury should always be suspected. A delay in diagnosis increases morbidity (Achildi et al., 2007).

**Infant animal models**

Large animal models used in spinal cord related scientific research are generally at least of adolescent age. Paediatric patterns of injury differ vastly from those of adults. The response to experimental treatment may also be at variance with that for adults because of significant differences between mature and immature neurological systems. Until recently, no suitable model for paediatric SCI existed. Dr Samdani presented preliminary work on an infant piglet model at the Howard Steel conference (Samdani et al 2009), the first large animal model for paediatric complete SCI. This model is proposed to:

1. Characterise pathophysiological differences between the adult and paediatric SCI;
2. Provide a model to evaluate experimental techniques and advances for SCI (e.g. transplantation of marrow stromal cells);
3. Serve a vital role in translating promising therapeutic strategies for paediatric SCI.
Activity based rehabilitation (ABR), when applied to SCI, is a term used to describe intensive, task specific, patterned, repetitive motion below the level of injury. Activation of the neuromuscular system aims to promote neurological recovery with the benefit of restoration of health and function.

Intensive gait training
A paradigm shift has occurred in the retraining of walking to emphasise intensity of practice. It has been demonstrated (Lang et al., 2009) that only 357 steps are achieved during a typical gait training session in a neurological rehabilitation setting and other findings suggest (Adolph, 1997) that thousands of steps are needed for motor acquisition, as demonstrated in healthy infants learning to walk. Promising evidence suggests that intense gait training may promote recovery of some form of walking in adults with SCI and that general health is promoted, or maintained. This premise has filtered though into the clinical practice and research of children with SCI.

Three main methods of repetitive gait training were observed on my study tour. (1) body weight supported treadmill training (BWSTT) with an upright harness system suspended over the treadmill; (2) Over-ground body weight supported training (OG) where the harness system is mobile, usually in a ceiling tracking system and (3) Robotic driven training using the Lokomat® (http://www.hocoma.com). The availability of equipment, staff resources, deemed suitability, response to a training trial period and the general philosophies of the facility determine what is offered to a particular child.

The premise of all these types of gait training is to capitalise on intact neural circuitry below the level of injury to regain stepping and possibly promote neural recovery. The locomotor ‘central pattern generators’ (CPGs), considered to be rhythm- and pattern-generating networks of the central nervous system (Guertin et al., 2009), are thought to be responsible for driving stepping patterns. CPGs are extensively researched in this field.

It is proposed that intensive gait training may have musculoskeletal and physiological effects on children similar to those that are the postulated benefits of standing (e.g. positive effect on bone density, improved gastrointestinal motility, stretching of two joint muscles and psychological benefits of being upright).

Below is a summary of observations and therapist discussion points in facilities that offer intensive gait training to children with SCI:

- Children less than approximately 5 years of age are sufficiently small to allow one therapist to facilitate stepping in both legs. A second therapist is required to operate equipment (e.g. treadmill or guidance of the body weight support harness). Despite the relatively low mass of the child’s legs the repeated facilitation of stepping can be physically fatiguing for staff.
- BWSTT for older (and heavier) children is significantly labour intensive. Often 3 staff members are required. Physical demands are high and awkward postures are required by the treating therapists.
- The TheraStride™ is an innovative weight-bearing rehabilitation system for BWSTT that offers more quantitative information and comfort for the therapist than regular set-ups. A computer system drives the treadmill and the amount of support being provided. If appropriate, the child may operate the treadmill (thereby reducing the need for another staff member and giving the child more autonomy). The harness system may be used to facilitate the transfer from sitting to standing position. An available backrest and adaptable seat offer greater comfort and improved body mechanics for the treating therapist (KKI).
- The LOKO Station (Woodway) is the product of choice at Stoke Mandeville for BSWTT.
- The Guldmann system offers over ground training via a ceiling tracking system which is useful for transferring skills to a more natural surface. The harness however significantly alters gait mechanics unfavourably (i.e. places the patient in too much posterior pelvic tilt) such that training may not be efficient (KKI).
- The Lokomat® is a robotic driven gait orthotic that automates intensive walking practice over a treadmill. The recent availability of paediatric sized ‘legs’ allows fit and comfort for a child as young as 4. Motivational software is available to encourage participation and provide feedback for effort (e.g. a computer face smile increases as the child voluntarily contributes effort to stepping and takes more weight through the legs). While the initial outlay for the Lokomat® is estimated at US$300,000, labour intensity is reduced to one staff member and manual handling during treadmill training is eliminated. The resultant gait is smooth and closely resembles normal walking in the lower limbs. It does not allow for normal arm swing, due to the bulk of the equipment at the pelvic region. The stringent mechanical control of the Lokomat® does not provide opportunity for error or natural deviations in the gait cycle. Early work and thoughts of Dr Antoinette Domingo (post doctorate fellow) and Dr Tanya Lam (PhD Neuroscience) of ICORD suggest that this may be unfavourable for learning. Therefore this type of training may have maximum impact if combined with other, more varied practice that allows for error and self-correction.
- Intensive gait training is provided as part of a comprehensive rehabilitation regime (e.g wheelchair skills training, standing program, RGO training, education).
- Traditional clinical strategies are employed with intensive gait training, including mirror biofeedback, verbal feedback, encouragement and manual guidance.
- Training sessions typically last 45 - 60 minutes, 3 - 5 times per week for 4 - 12 weeks. No current evidence suggests an optimal dosage.
The most appropriate young candidates have at least have flickers of muscle activity in their lower limb musculature. It is considered advantageous if the child has some initial ability to stand and walk. However, children without any motor activity below the level of the lesion are given the opportunity to train in this way.

In an energetic presentation at the 2009 Howard Steel Conference, Andrea Behrman (PhD, PT) listed guidelines for intensive gait training from her extensive work in this field (Behrman, 2009a):

1. Maximise loading on the lower limbs. Minimise or eliminate loading on the upper limbs.
2. Optimise posture and kinematics in every movement.
3. Provide sensory input consistent with walking activity.
4. Maximise independence and recovery of movement while minimising compensatory strategies.

At present, no large scale clinical trial has been published to substantiate a physiological, neurological or functional benefit of these types of training in humans. However, case studies have been published detailing recovery of stepping with intensive gait training in some adults (Behrman & Harkema, 2000; Field-Fote et al., 2005) and children with SCI (Behrman et al., 2008; Behrman et al., 2006). Long term adaptations are yet to be explained. A video example of Dr Behrman’s gait retraining in a child is available at http://ptjournal.org/cgi/content/full/88/5/580/DC1.

**Gait training with additional sensory input**

Sensory or afferent information is inherent in walking of any form. During my study tour, I noted that therapists worked to create sensory experiences consistent with normal walking (e.g. reciprocal arm swing, a fair cadence, weight shift and pressure through the heel at initial contact). The table below outlines the work of researchers whom I met, investigating effects of adding other sensory stimuli to intensive gait training. Such additions are hypothesised to tap into intact neuronal pathways, further stimulating central pattern generators.

Publications from this work are pending.
CURRENT INVESTIGATIONS OF INTENSIVE GAIT TRAINING WITH ADDITIONAL SENSORY INPUTS

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<tr>
<td>Andrea Berhman*, University of Florida and Brooks Rehabilitation</td>
<td>BWSTT &amp; Overground (children)</td>
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<td>Auditory (acoustic startle response)</td>
<td>Intact reticulospinal tract</td>
<td>2/5 children recovered walking, 3/5 children improved in skills that were critical to function (e.g. trunk control)</td>
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<td>Edelle Field-Fote &amp; Kathleen Manella, The Miami Project to Cure Paralysis**</td>
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<tr>
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<td>Robotics - Lokomat (adult)</td>
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* The Kids STEP (STEpping Excites Plasticity), supported by Craig H Neilson Foundation. See [http://locomotor.phhp.ufl.edu/kidsstepstudy/](http://locomotor.phhp.ufl.edu/kidsstepstudy/)


*** Robotics-Locomat (adult) [http://icord.org/research-studies/current-study-lokomat-training/](http://icord.org/research-studies/current-study-lokomat-training/)

Neuromuscular Electrical Stimulation

Neuromuscular electrical stimulation (NMES) has been used in physiotherapy practice for decades. It is the application of an electrical signal applied to a nerve or muscle for the purpose of creating muscle contraction. Functional electrical stimulation (FES) is the application of NMES to create purposeful movement for achievement of a specific activity. Novel applications of NMES and FES in child spinal cord injury were observed on my study tour.

Drop foot stimulators

At the National FES Centre, UK, I completed a highly recommended two day FES course and drop foot stimulator accreditation. The course was delivered by Odstock® Medical, a National Health Service (NHS) company enabling expansion of the FES service at Salisbury District Hospital. The main device discussed at the course was the new design single channel Odstock® Dropped Foot Stimulator (ODFS®) – Pace V1.0, a foot switch controlled neuromuscular stimulator, constructed to achieve foot lift during swing in the gait cycle. It is suitable for people with upper motor neuron lesions such as spinal cord injury, with some level of walking ability. The ODFS® Pace may substitute traditional ankle-foot-orthotics (AFO) with
the added benefit of a short-term "carry-over" effect in some populations (Taylor et al., 1999b). Evidence suggests an orthotic benefit by increasing walking speed by 27% and reducing the energy cost of walking by 33% in people with neurological conditions (Taylor et al., 1999b). Ingrid Wilkinson, Research PT, with whom I spent one valuable clinical day, highlighted successful outcomes achieved for children with cerebral palsy. Since returning to Australia, I have fitted the ODFS® Pace to an adolescent with a Brown-sequard presentation of SCI and observed immediate positive outcomes. Further work is warranted in children with SCI.

Drop foot stimulators are available from other manufacturers such as WalkAide® and Bioness®. Cost and set-up procedures vary considerably. Bioness® has also released an upper limb stimulator system for grasp (NESS H200 Hand Rehabilitation System, http://www.bioness.com).

**FES Cycling**

The most frequent clinical application of FES in children is cycling on a stationary bike. The equipment used almost exclusively at the facilities visited was the RT300-P FES cycle (Restorative-Therapies, Inc., Baltimore, MD, US, http://www.restorative-therapies.com, Paediatric model). Individual user data stored and accessed via the internet, enable remote program modification.

Goals of FES cycling relate to health benefits attained by whole body exercise in the general population. Recent evidence substantiates the positive effects FES cycling on VO2 max, a measure of cardiovascular efficiency (Johnston, Smith et al., 2009) and bone density (Johnston et al in press) in children with SCI. Studies suggest a positive effect on muscle volume, stimulated muscle strength (quadriceps) and resting heart rate in children (Johnston et al 2008), although subject numbers were low and passive cycling (i.e. without FES) produced some of these benefits.

The efficacy of FES cycling on the neurological system or functional gain in children has not to date been demonstrated. Several facilities that I visited employed FES cycling for the aforementioned health benefits as well as potential stimulation of CPGs and neurological recovery. A typical regime was 45 minute sessions 3 times per week, with subject dependent stimulator and revolution variation. Most therapists reported a loss of observed benefits on cycling cessation, similar to loss of benefits with cessation of regular exercise in the general population. Certainly, the participating children and young people observed by me reported high satisfaction with outcomes. Examples are reduced lower limb spasticity enabling greater comfort and improved sleep, a general feeling of well being not experienced with other therapies, psychological satisfaction of seeing their legs move and improved body awareness. Families often sought financial
support or funding to purchase an FES bike for home use. Purchase price is approximately US$15,000. The viability of FES cycling in the home with parental guidance has been demonstrated (Johnston, Smith, Oladeji et al., 2008).

At the Shriners Hospital for Children in Philadelphia, I was privileged to confer with Associate Professor Therese Johnston, a global authority on FES for children with SCI. Key points from our discussion are listed here:

- Upper limb ergometry* is an activity vastly enjoyed by children with SCI. The main drawback is this activity cannot generally be sustained beyond 10 minutes by children, due to small capacity of upper limb muscles, high demand on the cardiovascular system and possible altered response to exercise due to injury. On the other hand, lower limb FES cycling can be sustained for as long as 60 minutes and preserves the upper limbs for daily activities (e.g. wheelchair propulsion, use of a gait aid).
- Children with tetraplegia (and thus dysfunction of the sympathetic part of the autonomic nervous system) hit a maximum heart rate of about 130bpm when cycling. Heart rate may not be a reliable method of measuring exercise intensity or exercise response in this population. Further research is required on the cardiovascular response to exercise in SCI children (Johnston, Smith, Betz et al., 2008).
- A combination of upper limb ergometry (or FES driven ergometry) and lower limb FES cycling may be the best option for exercise in these children.
- Better mechanical alignment and improved efficiency of the cycling action is achieved with a biarticular ball and socket shank guide attached to the pedal of RT300-P FES Cycle (see Johnston, Barr et al., 2008). Even with this additional guide small limbs can be difficult to align and fitting should be monitored by a trained professional (also see Johnston, Betz et al., 2009).
- Legs must be supported during cycling to avoid adduction and internal rotation of the hip while cycling (Johnston, Betz et al., 2009).

* Upper limb ergometry is a relatively inexpensive and readily available form of continuous arm exercise. Several models are commercially available (e.g. Saratoga Silver ergometer). Three Rivers Holdings recently launched the Nintendo GameCycle ([http://www.3rivers.com/GameCycleGateWay.php](http://www.3rivers.com/GameCycleGateWay.php)), a considerably more expensive, but notably more motivating and interactive form of arm cranking. Most of the centres that I visited have the GameCycle.

Dr Calum McRae and colleagues from Shriners Philadelphia has extrapolated the FES cycling concept to a child specific over-ground model. He devoted considerable time explaining to me the development and testing of this exciting new concept for children. He also highlighted challenges with current stimulation techniques and design features that need further development before release to the commercial market.

A model described in (McRae et al., 2009), consists of a sport tricycle designed for children (KMX Karts, UK [http://www.kmxkarts.co.uk](http://www.kmxkarts.co.uk)) with instrumentation provided to specification by Hasomed GmbH. This
type of model is favoured for recreational pursuits and arguably more fun and engaging for a child than stationary FES cycling. The Hasomed RehaBike (Hasomed GmbH, Magdeburg, Germany [http://www.hasomed.de]) is commercially available for adults with some features suitable for children. This over-ground FES bike has a drawback of automated control of pedaling motion while the model devised by Dr McRae enables direct control over pedaling speed by a feed-forward loop and allows a child to control the level of stimulation with a hand-held throttle as well as steer the bike.

While the feasibility of this model has been demonstrated (McRae et al., 2009), two areas require further development:

1. Accurate measurement of propulsive and resistive torque in order to calculate values required for sustainable forward propulsion. In contrast to stationary cycling, the mass of the system and rolling resistance (e.g. friction from the tyres) are problematic for cycling for long duration and distances.
2. The artificial motor unit recruitment achieved with current stimulation parameters rapidly fatigues the small, immature muscles of a child.

With improved features, such a tricycle is envisaged to facilitate spontaneous interaction with peers, access to outdoors and to allow achievement of a broad range of health benefits.

**FES Rowing**

Although I did not encounter facilities that offered FES rowing in my tour, I was referred to Robin Gibbons, a UK based competitive rower with paraplegia. With his team, Robin has pioneered the application of FES to rowing to achieve a whole body workout and option for sports and leisure. Through email contact, Robyn has discussed with me his support of a child in NSW to achieve exercise by rowing. The literature describes the feasibility of indoor FES rowing in adults as an option to attain sufficient exercise volume and intensity for health benefits (Hettinga & Andrews, 2007). The UK FES rowing team aim to increase participation further through internet rowing and on-water events (see [http://www.fesrowing.org/index.html](http://www.fesrowing.org/index.html)).

**Therapeutic NMES**

NMES is offered extensively in isolation or as part of traditional therapy at both Gillette’s Children’s Specialty Health Care and Kennedy Krieger Institute (KKI). At ‘Camp Kennedy’, a Saturday gym program for SCI children at KKI, I observed the application of NMES to abdominal and erector spinae muscles during sitting balance and wheelchair transfer tasks. This was postulated to enhance internal trunk stability and further engage a young nervous system in activity. On my clinical visit to Salisbury National FES Centre, Dr Paul Taylor reported the incidental discovery of benefit to blood pressure with abdominal muscle NMES...
during investigations of FES for enhanced cough.

In another clinical session at KKI, NMES was used to evaluate the suitability of a 4 year old for FES cycling, maintenance of muscle bulk and skin health, ‘nourishing’ and ‘priming’ neural pathways. The dual channel Empi 300PV™ (http://www.empi.com) is the model of choice for partially innervated muscles, due to its portability, multiple functions and external trigger capabilities. For apparent denervated, or flaccid muscles, long duration pulses (1 ms) were applied using the ‘Swiss stim’ unit. While such pulse widths carry an inherent risk of tissue damage (e.g. burn), clinicians and patients agreed on the advantages that this type of stimulation offers when no other options are available for muscle contraction. Long pulse stimulation for this purpose has been available for decades but not widely practised (Woodcock et al., 1999).

**Keeping it moving – other dynamic equipment & strategies**

A prominent universal observation during my study tour was that people with SCI are engaged not only in intensive, physically demanding programs but that they are frequently upright and involved in dynamic (rather than static) and weight bearing /closed-chain activity.

Focussing on the nature and broad developmental needs of children, paediatric therapy in Australia (and around the world) has traditionally emphasised standing programs, supported mobility (e.g. RGO walking) and therapeutic play in a variety of physical positions and natural environments.

From my study tour, I deduce that the following concepts appear to influence innovative practice:

1. General SCI therapy makes use of traditional paediatric practice models such as standing programs, closed chain upper limb weight bearing floor programs and developmental sequencing activities.
2. There is a higher expectation to involve body parts below the level of injury.
3. Focus should move away from static, reduced gravity postures that are detrimental to all body systems (musculoskeletal, neurological and cardiovascular, etc) and limit function to stereotyped, repetitive movements.

Equipment and strategies influenced by these concepts, not discussed elsewhere in this report, include:

- Upright elliptical devices: a) EasyStand Evolv™ Glider™ (http://www.easystand.com/evolv-glider, KKI and Project Walk) and body weight support harness system suspended over an elliptical cross trainer (Project Walk) for weight bearing reciprocal leg motion. Elicited autonomic dysreflexia with elliptical action precludes some individuals from using these devices.
- TheraSuit™ - a body suit attached to a therapy cage by elastic bungies to achieve improved body alignment and enhanced feedback while offering either movement support or resistance (part of the “SuitAbility” program at Children’s Hospital Miami and Easter Seals DuPage, centres that specialise in a range of juvenile neuromuscular disorders which may include SCI). The
manufacturers of TheraSuit™ have devised a specific program for adolescents and adults with SCI (http://www.suittherapy.com/therasuit_for_spinal_cord_injury.htm).

- Elevation™ (pictured right), which allows instant adjustment of wheelchair seat height, angle, backrest angle and tilt (Instinct Mobility http://www.UseYourInstinct.com). Dr Jaimie Borisoff at Neil Squires Society, ICORD, creator of Elevation™, demonstrated to me the versatility of this system. Customers have reported greater function, independence and comfort with use, compared to their regular seating system. This product has recently been made available in Australia (http://durmed.com.au).

- Adaptation of commercially available toys. For example, Staff at KKI adapt the ‘Amtryke’ (pictured left, http://www.amtrykestore.org/) on an individual basis for small children with SCI, allowing parent or upper limb assisted reciprocal arm and leg motion. Therapeutic elasticised leg wraps or attached shank guards are used to improve lower limb biomechanics.

- Use of Pilates reformers to encourage core strength, breathing control and flexibility as part of an SCI or childhood neurological condition (Project Walk and Easter Seals DuPage).

- Whole body vibration machines (e.g. Power Plate® http://www.powerplate.com.au), employed at various centres to increase muscle contractions and stimulate the nervous system. Easter Seals DuPage and Project Walk use this equipment in their programs. In the Miami Project, whole body vibration is being investigated as an adjunct to gait retraining in adults and children.

- The Dardzinski Method™ - a 5 phase ‘exercise based recovery’ program offered by Project Walk to adults and children with SCI (http://www.projectwalk.com). The program encompasses a range of weight bearing, strengthening and active assisted activities with a more play / game based approach for children. Candidates are discouraged from wearing supportive and protective gait aids, such as lower limb orthoses during training. This program has been discussed in more detail in the Churchill Report of Professor Mary Galea http://www.churchilltrust.com.au/fellows/detail/3092/.

At the time of writing this report, scientific evidence to quantify the effects of any of the above equipment or strategies within the paediatric SCI population was not available.
Best position, best part of the day

The old tale of “pull that face for long enough, the wind will change and you will be stuck like that forever” is sadly somewhat true when considering the effects of SCI on the growing body. Two major manifestations of SCI, especially when coexisting, can have devastating effects on a child’s musculoskeletal system. The first is paralysis, resulting in reduced or absent, imbalanced movement. The second is spasticity, abnormal reflexive movement, causing stereotyped movement patterns.

Common musculoskeletal anomalies observed in children with acquired spinal cord injury include:

- **Scoliosis**: if injury is sustained prior to the adolescent growth spurt, incidence is up to 98% of all cases (Betz, 2009b; Mehta et al., 2004). Scoliosis is more severe with (1) injury at young age (2) paraplegia when compared to tetraplegia and (3) complete injuries. Noteworthy is the fact that, while scoliosis is more severe in younger children, it is slower to progress than the less severe but faster progressing scoliosis in older children (Bergström et al., 1999, Bergström, 2009, ISCoS presentation).
- **Hip dysplasia**: 100% incidence of hip joint dislocation if injury sustained between 0-5 years of age and 60% incidence if injured between the ages of 6-10 (Betz, 2009b);
- **Pelvic obliquity**: intimately related to scoliosis and hip dysplasia;
- **Leg length discrepancy**: ‘apparent’ – related to pelvic obliquity and hip subluxation / dislocation or ‘true’ – related to unequal weight bearing for long durations over growing years;
- **Reduced growth in long bones**: related to reduced use and weight bearing and contributing to true leg length discrepancies;
- **Metacarpophalangeal joint contractures**, related to muscle imbalance ± spasticity;
- **Scaulothoracic instability and dysfunction**: adversely affecting hand and arm function;
- **Fixed flexion contractures** at the elbows and knees, related to muscle imbalance ± spasticity, sleeping and wheelchair positions;
- **Low bone density** - 60% of age and sex matched peers (Lauer et al., 2007).

In children with physical disabilities, techniques and equipment employed to achieve optimal ‘24 hour positioning’ for minimisation of secondary complications are well established in Australia. These include individualised wheelchair seating, adaptation of sophisticated standing frames, application of custom splinting, casting and orthotics. The following section contains items of information discovered on my study tour on novel knowledge and tools, either in structure or by application to children with SCI.

**Night time positioning**

- The recommendation that children over the age of 1 year sleep in the prone position to achieve long duration stretch to the hip flexor muscles and knee joints and also to establish long duration posterior pressure relieving habits (Stoke Mandeville and Miami Physical Therapist Inc.). Comfort in this position may be enhanced by a contour device such as the ‘bodyCushion™’ (recommended at Miami Physical Therapist Inc.).
Night wear of the ‘Contour V’ hip abduction soft brace (pictured right) for prophylaxis of hip dysplasia (DM Orthotics Ltd, www.dmorthotics.com). This brace is less restrictive than a sleep system and assimilates the closed packed position of the hip (recommended at Stoke Mandeville).

Night wear of custom made splinting in the ‘intrinsic plus position’ of the hand, to ameliorate risk of metacarpophalangeal joint deformity in children with cervical level SCI. (Shriners Hospitals).

Scoliosis prophylaxis & conservative management

- If the child is yet to reach skeletal maturity, prophylactic provision of a custom made thoraco-lumbar-sacral-orthoses (TLSO) is strongly recommended as soon after injury as possible (Dr Randy Betz, Shriners Philadelphia and Ebba Bergström, Stoke Mandeville).

- Early use of a brace has the advantage of initial skill training (e.g. wheelchair transfers) occurring within the brace. Kirsten Hart, Senior PT at Stoke Mandeville believes that if children learn a skill and continue to practice this skill within their brace, then they may be less likely to encounter the functional restrictions frequently reported by brace users (Chafetz et al., 2007; Sison-Williamson et al., 2007).

- In established curves:
  - Less than 20°, bracing may reduce the need for corrective surgery from 90% to 50%. For those that will ultimately require surgery, bracing is likely to delay surgery timing and thus allow more years of skeletal development.
  - Between 21-40°, bracing plays a lesser role in preventing progression.
  - Greater than 40°, bracing probably has no beneficial role (Betz, 2009a, 2009b, 2009c). Due to the challenge of equally distributing forces within the brace, skin integrity may be jeopardised

- While awaiting provision of a custom made TLSO, application of an abdominal binder assists in establishing routines by “getting the child and family used to putting something around their torso” (Kirsten Hart, Stoke Mandeville). Compliance challenges with brace wear are well established in this population (Hunter et al., 2008). Abdominal binders may have the added benefit of improving cough effectiveness and blood pressure in compromised children.

- Construction of a TLSO with natural materials (leather with metal boning and sheepskin) have proved to be clinically effective and are better tolerated than rigid thermoplastics for straight spines in small children (Kirsten Hart, Stoke Mandeville).
Achieving upright mobility

Orthoses & FES
Orthotheses have been employed for standing and upright mobility in this population for decades. Traditional joint control devices include knee-ankle-foot-orthoses (KAFOs) and arrays of ankle-foot-orthoses (AFOs) including newer varieties of carbon fibre composition. Useful in the clinic are adjustable training AFO and KAFO braces which I observed at Stoke Mandeville and Shriners Philadelphia (http://www.alimed.com). Other supportive devices are hip-knee-ankle-foot-orthoses (HKAFO), reciprocal gait orthoses (RGOs) and parapodia (Vogel & Lubicky, 1995). In these systems, useful for therapeutic purposes mostly, walking is limited to short distances (e.g. in the classroom). This is due to the high energy demands and the cumbersome nature of unnatural straight legged stepping or swing through movements.

Implanted functional electrical stimulation (FES) also used for decades to achieve standing and upright mobility has never gained widespread popularity. FES for this purpose has been shown to be equivocal (Bonaroti et al., 1999a) or offer only slightly more function compared to conventional orthoses (Bonaroti et al., 1999b; Johnston et al., 2003).

Dana Robertson, PT Shinrers Philadelphia, demonstrated the Parastep® (Sigmedics, Inc., Fairborn, OH), a commercially available surface FES system with portable stimulation device attached to a type of ‘pick-up-frame’ that comes with the system for upright mobility. Dana shared her clinical experience with me for this system, that despite the potential functional and health benefits, the Parastep® has not been overly successful with children due to the long and stringent training program required and large size of the walking aid.

An excellent review of this topic is available at (Chafetz et al., 2005).

Stance control orthotics (SCO, pictured right) are a new generation of knee controlling devices that hold promise for a more normalised, efficient and less exhausting gait pattern. Joanna Kanas, PT, registered orthotist and prosthetist, shared her expert clinical opinion and experiences with me in the workshop at Shriners Philadelphia. Below are points of understanding from this discussion:

- SCO are the main new advance that will benefit children with SCI. They offer stability in stance and, unlike conventional orthoses, offer free knee flexion in swing. At initial foot contact, a foot switch signals engagement of an extension locking mechanism at the knee (the introduction of
the article by (Lemaire et al., 2009) provides a good overview of different stance control approaches.

- Stance control is typically integrated into conventional KAFOs, but may also be integrated into an RGO.
- SCO are significantly lighter than conventional, equivalent orthotics.
- A degree of muscle control is required in the hip flexors and extensors to initiate stepping if SCO is fitted to a KAFO.
- Stance control applied to an RGO requires minimal hip muscle control to achieve reciprocal stepping.
- Some SCOs offer ‘stumble’ control whereby, regardless of the knee position at initial foot contact, the system will still lock thereby preventing a trip or a fall. This model requires less proximal stability (i.e at the hip and pelvis) than models without this feature.
- Available mechanical SCOs include Horton Stance control SCOKJ, Becker Orthopaedics Fullstride, Otto Bock FreeWalk.
- Growth in children is the single biggest challenge, as system cabling is expensive and cannot be ‘expanded’ easily.
- Cognitive ability needs to be considered before prescription, as rehabilitation to become proficient with SCO is intensive.
- Electronic and microprocessor controlled SCO are also available (e.g. Becker E-Knee and Otto Bock SenorWalk). These are not currently suitable for children due to bulk and are also very noisy. Current cost may also render them not viable due to frequent ‘growth’ of the system required with child growth (as for SCOs but systems are several fold the expense).
- Hyper-lordotic postures of the lumbar spine, biomechanically dictated in ‘parastance’ and ‘swing through gait’, are lessened with stance control in situ. Children who stand and walk with high support orthotics typically develop fixed lumbar spine deformities of this nature. This musculoskeletal anomaly may be mitigated with the advent of SCOs into their standing mobility systems.

In the Motion Analysis Laboratory at Shriners Philadelphia, David Hutchinson, PT, discussed with me his research initiatives comparing SCO with conventional orthoses in children with SCI. In a single case study design, he noted that an SCO was preferable to conventional KAFO due to its light weight, less bulky design and child perceptions of a more normalised gait pattern. The motion analysis trace was suggestive of the same. An added benefit to the SCO was that the subject was better able to manage transitionary movements, such as sit-to-stand. He presented some of his findings at the Howard Steel conference (Hutchinson, 2009).
A standing personal transporter
When child bipedal mobility and whole body endurance are compromised by SCI, alternative forms of mobility are required. It is imperative that they be safe, efficient, suit child ability, are minimally stressful on the growing body and allow maximum accessibility. Wheelchairs with individualised prescription, correct maintenance (e.g. tyre pressure, Sawatzky & Denison, 2006) and skills training adequately fulfil these criteria.

A standing mobility device, in particular, the Segway Personal Transporter (Segway Smart Motion™ http://www.segway.com/personaltransporter), has been proposed for those that are able to stand or ambulate short distances, as an alternative to a wheelchair for mobility over longer distances. The Segway consists of a small standing platform embedded with gyroscopes to maintain the upright position. It has handlebars for grip and steering and an electric powered motor that translates the system forwards or backwards, depending on which way the user leans. It can travel as fast as 20km / hr and is reported to cope with challenging terrains (unlike the average wheelchair).

I discussed the use of the Segway device with investigators and clinicians, namely, my host at ICORD, Associate Professor Bonita Sawatzky, her Masters student Grace Boutilier as well as Ian Denison, PT and wheelchair skills trainer at GF Strong. Their results have confirmed the viability of the Segway for a range of neurological conditions, psychological benefits of being upright and social acceptability (Sawatzky et al., 2007; Sawatzky et al., 2009). Feedback from subjects to Grace Boutilier includes less pain, reduced fatigue and spasticity.

For people that would otherwise use a wheelchair for long distance mobility, the Segway has potential to (1) alleviate upper limb overuse syndromes (2) provide opportunity for standing balance practice and (3) reap benefits of weight bearing in daily activities. Notwithstanding, the concept of power standing mobility has limitations and potentials, hence improved creative design and further research are warranted.
Surgical considerations

In this section common surgical procedures for children with SCI are surveyed. It is important that therapists, both physio- and occupational, understand available options and procedural specifics. Therapists have a pivotal role in multidisciplinary decision making regarding candidature, timing, nature of surgery and post operative rehabilitation. Surgery aims to optimise function and minimise secondary complications of childhood SCI.

I was privileged to attend multidisciplinary paediatric SCI clinics of highly regarded orthopaedic specialists, Dr Randy Betz of Shriners Philadelphia and Dr Beauchamp with Carol King, PT of British Columbia Children’s Hospital and also an energetic ward round with Dr Larry Vogel and his team at Shriners Chicago. I watched clinic assessments and listened to the rationale for their established procedures (e.g. scoliosis) and techniques not so commonly observed in Australia (e.g. scapular stabilisation and tendon transfers in children with SCI). Discussions and subsequent email correspondence with Associate Professor Mary Jane Mulcahey, OT and Professor Scott Kozin, highly accomplished Hand and Upper Extremely Surgeon, have added to my knowledge base.

Scoliosis correction
The decision to correct an abnormally curved spine is not considered lightly. Sixty-seven percent of children injured prior to skeletal maturity will require surgery (Betz, 2009b). By the time corrective scoliosis surgery is performed, it is probable that a number of compensatory strategies have been developed in an effort to maintain as much independence as possible. Conventional scoliosis surgery aims to reduce abnormal ‘bends’ in the coronal plane and rotational deformities (Tredwell et al., 1999) ultimately to restore ‘normal’ spinal curvatures (in both the coronal and sagittal planes). Instrumentation such as flexible rods and multiple hooks (e.g. Texas Scottish Rite Hospital (TSRH) technique) are frequently used.

A paradigm shift is occurring both in the methods of surgery and the evaluation of the young person prior to surgery. A therapist’s assessment of how the young person functions best, together with analysis of compensatory strategies and adopted spinal postures, may influence the outcome of the corrected spine. For instance, if a young person does not use standing for their mobility (i.e. uses a wheelchair) and takes advantage of a slightly kyphotic posture to perform daily tasks (e.g. brushing own hair), a surgical change to achieve ‘normal’ spinal postures may jeopardise their independence. New thoughts challenge the multidisciplinary team to consider what may be ‘normal’ sagittal spinal curves for a young person with SCI and how these may be advantageous for function.
The table below is the work of Dr Randy Betz of Shriners Philadelphia profiling Cobb angle measures of ‘normal’ and SCI spines, presented at the Howard Steel Conference (Betz, 2009a).

<table>
<thead>
<tr>
<th>Normal Spine (Sagittal Cobb angle)</th>
<th>SCI Spine (Sagittal Cobb angle)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thoracic kyphosis 38.5° (±8.1)</td>
<td>40.2° (±9)</td>
</tr>
<tr>
<td>Thoracolumbar region 5° (±10)</td>
<td>19.1° (±8)</td>
</tr>
<tr>
<td>Lumbar lordosis -56.6° (±9.1)</td>
<td>-8° (±12)</td>
</tr>
</tbody>
</table>

Such information may influence the type of surgical correction. Dr Betz and his colleagues have results of work in press detailing the use of wedge osteotomies for fusionless treatment (McCarthy et al., in press) which may further revolutionise management of the scoliosed spine.

For spinal Xray procedures, I learnt of an established practice at Stoke Mandeville, whereby a physiotherapist supports a child in positions under gravity on their usual seating systems during irradiation. This information may also prove useful in understanding more about spinal curvatures of children with SCI.

**The problematic hip**

Management of a subluxed or dislocated hip in the child with SCI remains a surgical challenge. Current conservative measures are ineffective or at best limited in mitigating this very common problem. Hip dysplasia in the child may affect upper limb function due to seated positioning imperfections and also affect fulcrums of lower limb muscles during FES cycling (Betz, 2009b). Hip dysplasia persisting in adulthood may cause pain, challenge sitting balance and trigger autonomic dysreflexia (McCarthy, 2009). Surgery aims to correct soft tissue deformity and achieve bony stability with more novel approaches, paying particular attention to the acetabulum (McCarthy, 2009).

**Scapular stabilization**

Scapulothoracic instability management has moved away from joint fusion to the technique which allows some scapular thoracic motion. The procedure is (1) AO plate is screwed into lateral wall of the scapula; (2) Fascia lata allograft and mersilene tape are used to hold scapula to the ribs; (3) reconstruction plate is fixed to the 8th rib to span the inferior pole of scapula. This is successful in providing the upper limb with some dynamic stability for function (Betz, 2009c).
Tendon transfers

Dr Scott Kozin and his team at Shriners Hospital for Children Philadelphia have been pioneers for decades in restoring upper limb function in children with cervical SCI and other conditions. Their work on the tetraplegic hand and arm is strongly focused on tendon transfers, augmented by other procedures such as arthrodesis and tendon lengthening (Mulcahey, 2009a).

Tendon transfers capitalise on the scenario of having two or more muscles that perform a similar function across a joint. Part of the procedure is to move one of these muscles to restore a function lost through paralysis of other muscles. For example, a child with a C6 complete injury may lose the function of elbow straightening, but retain strong elbow bending. As elbow bending motion can be created by the brachialis and biceps muscles, the biceps could be moved to insert into the paralysed triceps muscle to recreate the lost elbow straightening.

Other procedures include:

- Transfer of brachioradialis to extensor carpi radialis brevis to restore active wrist extension with flexor pollicus longus tenodesis to restore passive pinch;
- Brachioradialis to flexor pollicus longus to restore active pinch;
- Extensor carpi radialis longus to flexor digitorum profundus to restore active grasp.

The post-operative rehabilitation generally includes 3 phases:

1. Immobilisation Phase (1-3 weeks)
2. Mobilisation Phase (3-6 weeks)
3. Strengthening and Functional Retraining Phase (6-12 weeks)

The International Classification System for Surgery of the Hand in Tetraplegia (ICSHT, McDowell, 1986) is used by the team to assess the young person’s suitability for the various upper limb procedures. Similar to the ASIA scale, the ICSHT has a motor component but it tests all key muscles of the upper limb. It also has a sensory component quantifying the presence of two point discrimination and ocular input.

I had the pleasure of meeting with Dr Scott Kozin and a number of his clients in the initial stages of their rehabilitation after restoration of upper limb function and also spent time in the inpatient gym with Sarah Ashworth, senior occupational therapist, observing the very first stages of post-operative rehabilitation. I also spoke with an adolescent who had undergone procedures to restore pinch and wrist extension many years prior. His prior implanted upper limb FES system was being removed as it had not been used since his tendon transfers. This young man beamed that tendon transfers was the most fruitful procedure he ever had undergone and that the function gained was used continuously.
Peer groups, participation & mentorship

One of the challenges of paediatric SCI is that its rarity renders opportunities to interact with others in a similar situation few and far between. This is strikingly apparent in Australia with a relatively low population scattered across an expansive geography and no dedicated rehabilitation facilities for children. It is arguable that children and youth with SCI, their families and siblings, would benefit from such interaction for modelling of positive behaviours, creative and peer directed problem solving, motor learning, identification and moral support through demanding transitions.

A second significant challenge is that spinal cord injury may pose a major disruption to a child’s ability to play and participate in typical childhood and adolescent roles. Play and participation are considered cornerstones to growth and development and provide significant satisfaction to the individual (Johnson et al., 2007; Klaas et al., 2009; Mulcahey et al., 2009). Play and participation in childhood also develop skills and attributes required in adulthood for independence and valuable contribution to society.

A third significant and alarming challenge is that children and youth (in the US) with SCI are evidently participating less than their able bodied peers in organised and spontaneous activity and that chosen activities are most frequently sedentary in nature (Johnson et al., 2004; Klaas et al., 2009). It is known that adolescents with SCI suffer an alarming high incidence (55%) of metabolic syndrome (Nelson et al., 2007), placing them at risk of cardiovascular disease and diabetes. They also suffer significantly lower health related quality of life compared to children and youth without mobility impairment (Abresch et al., 2007). In contrast, sports participation by adults (Hanson et al., 2001) and health status in adults who sustained their injuries during childhood (Anderson et al., 2003) have been associated with higher levels of community integration.

An excellent workshop run at the Howard Steel conference* conveyed the most recent evidence relating to participation by youth with SCI. Listed below are some important observations:

- Youth with SCI participate more in informal activities; most often in recreational and social, least often in physical activities.
- As youths age, overall participation decreases.
- Older youth participate with a more diverse group of people, further from home.
- There is a gender gap, with girls participating in a greater variety of activities more often and with a higher enjoyment level.
- Level of injury is related to diversity and intensity of activities.
- Caregiver educational level affects diversity of activities.
- Youth with SCI report a high level of enjoyment when they do participate.
- Youth without physical impairments are participating more than they ever have in organised activities. In contrast, youth with SCI have poor involvement.
- Perceived barriers to participation are not frequently reported. However when they are, the top two barriers are: (1) physical limitations and low independence and (2) lack of accessibility in the community.
Those in rural locations more frequently report environmental / community barriers while those in urban locations more frequently report their own physical impairments as being barriers.

* Sara Klaas, Erin Kelly and Julie Gorzkowski of Shriners Hospital for Children, Chicago, ran this workshop and are the authors of a publication presenting much of this work (Klaas et al., 2009).

A number of centres that I visited have developed group programs to facilitate participation and increase physical activity within the paediatric SCI population. Examples are:

- SCI Quad Camp (Shriners Chicago) - Quad rugby, waterskiing, outdoor adventure, scuba diving, sailing, fitness, meetings with successful adults with quadriplegia, independent living skills training
- SCI Sport & Conditioning Camp (Shriners Chicago) - Range of wheelchair sports (sled hockey, basketball, kayaking), social outings and awards ceremony
- G.L.A.H.M. Camp (Shriners Philadelphia) – Good Living And Healthy Mind camp filled with social evening events, pampering and other activities
- Shake-a-leg (associated with The Miami Project) – offering a wide range of water sports and education for people with a range of disabilities
- Wheelchair sports and training camp (Sunny Hill) - sport skills and games based wheelchair skills training, reverse integration (able-bodied siblings and friends also participate to learn skills and try wheelchair sports)

These groups are considered to be successful in creating a forum for peer support, mentoring, confidence building, improved health, providing experience of recreation options previously not attempted, establishing positive life-long habits of activity, developing independence and problem solving skills and expanding spinal specific knowledge. As these programs are generally run during the northern hemisphere summer I did not have the opportunity to attend any of them but I did liaise with staff who have been involved in developing or running these activities.

I visited Rancho Los Amigos National Rehabilitation Center on a day when their twice monthly evening SCI youth support group met. I was privileged to be welcomed and absorbed into the group, which, on this evening, developed strategies for improving communication and confidence skills. The energy of youths identifying with each other and problem solving together was a tremendously uplifting experience for all involved.

Krista Ash, Therapeutic Recreation Specialist at Gillette Children’s Specialty Health Care discussed with me a different approach to facilitating participation. She meets one-on-one with children post-injury to identify their strengths and passions in sport and leisure activities. Solution based strategies, education and local community information are provided to facilitate return to enjoyable and health giving activity. Her equivalent University qualifications are not available in Australia where this service is usually provided by a collaborative effort of social workers and physiotherapists.

Powerful incidental peer support was the product of simply having dedicated rehabilitation facilities for children and youth with SCI and a sizable population to ensure that sufficient numbers were undertaking
rehabilitation or review simultaneously. One youth with whom I reflected on benefits of meeting others with SCI stated, “We get to talk about personal experiences and give each other advice about easy ways to do things”.

Incidental mentor support was witnessed at facilities where children and adults share the same gym space (e.g. Stoke Mandeville, KKI, Project Walk). It is challenging to quantify the positive effect of this set-up but my perception and feedback from families is that it is invaluable to observe others at different stages post-injury. Young people look to adults as role models, inspired when they learn of working and married lives and motivated by observing each other working hard at achieving their goals despite their challenges.

World Wide Weehab – Rehab via the internet

It appears that the internet is being employed increasingly for delivery of rehabilitation, service provider communication and education. Clinicians and researchers are taking advantage of the immediacy, relative accessibility and data transfer capabilities of this medium. The list below captures the repertoire of internet uses encountered on my study tour. Some of the points have been mentioned elsewhere in this report. Not all are child specific.

- ReJoyce (Rehabilitation Joystick for Computer Exercise) workstation set up with a computer and webcam to complete virtual reality game exercises daily at home under the tele-supervision of a researcher from ICORD (Professor John Steeves, Dr Tania Lam). This was demonstrated to me by Katherine Pauhl. Research is currently in adults only. [http://icord.org/research-studies/in-home-study-for-improving-hand-function-with-functional-electrical-stimulation-and-virtual-reality-exercise/](http://icord.org/research-studies/in-home-study-for-improving-hand-function-with-functional-electrical-stimulation-and-virtual-reality-exercise/)

- Remote wound assessment software, currently being trialled by the outreach spinal team at Stoke Mandeville. A local clinician with limited experience in pressure areas (a common adversity of spinal cord injury) can capture data to send to the specialist outreach team for analysis.

- Restorative Therapies FES cycling systems: remote storage and progression of individual user settings via the internet “RTILink” [https://www.rtidatalink.com/datalink](https://www.rtidatalink.com/datalink)


- Web based exercise program to increase wheelchair activity in children, based on evidence that children who regularly participate in activity are more energy efficient at wheelchair propulsion. Children monitor activity using cycle odometers attached to their wheelchairs and record data weekly via website (Sawatzky et al., 2003).
- Use of Skype™ Voice over Internet Protocol (VOIP) by the Seating and Mobility outreach team at Sunny Hill Health Centre for Children. The team physiotherapist uses the videoconferencing feature for internet assessments to gather more information prior to an outreach visit.
- The SCI CAT: Paediatric spinal specific Computer Adaptive Testing Platforms. Currently being developed at Shriners Hospitals this outcome measurement system will gather data on activity performance and participation. Self reporting software is being developed with option of completion over the internet (Calhoun et al., 2009; Haley, 2009; Haley & Mulcahey, 2009; Hunter et al., 2008; Mulcahey et al., 2009)
- Gillette Children’s Specialty Health Care Interactive Spinal Cord Map: Teaches children about the spinal cord, how SCI happens, types of injury and implications, SCI ‘etiquette’, how to help someone with SCI, how to cope with their own emotions and preventative strategies [http://www.gillettechildrens.org/default.cfm?PID=1.7.22.3](http://www.gillettechildrens.org/default.cfm?PID=1.7.22.3)
Conclusions

The Dr Dorothea Sandars Churchill Fellowship 2009 has enabled me firstly to interact with and observe the work of outstanding professionals, secondly, to visit internationally acclaimed institutions that are globally recognised for research and management of spinal cord injury in infants and developing children and thirdly, to attend two very special conferences directly related to this field.

Topics relevant to my Fellowship brief are detailed in this report. Major lessons are outlined in the executive summary. Other pertinent observations are listed below:

From this study tour it is evident that;

- Professionals around the world are united in their passion and commitment to improve the lives of those affected by childhood spinal cord injury
- Emerging technology and tools point towards more accurate and reliable classification of childhood level of injury, which, in turn may be used to quantify effect of new therapies at biological and impairment levels.
- Results from new measurement tools and 3D motion analysis may be used for informed clinical decision making and enhance understanding of this population.
- Greater emphasis is being placed on intense physical programs that stimulate activation of the body below the level of injury, often referred to as ‘activity based therapy or rehabilitation’. This is a ‘hot’ and exciting topic around the world in both adult and child practice.

Growing evidence substantiates positive health benefits for children such as improved cardiovascular efficiency, lipid profiles, bone density, non pharmaceutical spasm control and increased muscle bulk protecting against skin sores and breakdown. Strong evidence does not yet exist to substantiate neurological recovery. There is a danger in creating unrealistic expectations of these types of therapies. It is of paramount importance that clinicians are clear in their advice about what outcomes can be expected from participating in such therapies.

It is critical that children have access to these therapies for health benefits and any other possible benefits yet to be substantiated by research. It is equally critical, that such therapies are part of a comprehensive, specialist guided model of care. This should encompass, but is not limited to, strategies to mitigate musculoskeletal complications in the growing body, provision of equipment and teaching of skills that maximise independence in daily life and community access, evaluation for specialist surgical procedures and support for adjustment to injury. Neglect to these latter things is likely to be of significant harm to the child and family’s overall health, well being and community integration.

- Spinal cord injury is not a reportable condition in any of the countries visited. Significant and large volumes of data pertaining to childhood SCI are available in the US and UK due to long histories of service and comparatively large populations. Shriners Hospitals, Rancho Los Amigos
National Rehabilitation and Stoke Mandeville Hospital have each served children with SCI for no less than 30 years.

- In the countries visited, organisations specifically designed for children with SCI are well resourced and equipped with the most recent technologies. Staffing levels support intensive therapy programs varying between 2-6 hours per day most days of the week. Children are invited to return at regular intervals (until they reach 18 or 21) for further intensive blocks of therapy and medical review.

- In well resourced facilities, staff are able to experiment with novel treatment strategies and equipment. This clinical work subsequently drives research and development in technology. Quality outputs enhance the profile of an organisation, in turn enhancing promotional strength and attracting donations and government funding. Such funds are then recruited into further resourcing and research.

- Significant service provision occurs abroad in dedicated paediatric rehabilitation facilities to which children and families must travel. Children may be inpatient or outpatient.

- Outreach services in the US and Canada are structured such that a team relocates to a regional centre and children are seen as outpatients. The Outreach service in the UK extends to the home but clinicians are adult trained. This service is underutilised by children and their families.

- Northcott Disability Services, the Spinecare foundation and members of the NSW Paediatric Spinal Outreach Service should be commended on their model of service that supports children and families in their natural environment and aims to maximise community integration.

- In Australia, funding, availability of resources and geographical spread of a small population are significant challenges in providing a comprehensive children’s spinal service. The intensity and longevity of the service required to support the changing needs of an individual growing up with a SCI are yet to be fully catered for and acknowledged here.

- Australians are highly regarded and globally acknowledged for their work in adult spinal cord injury.

- In the US, a significant number of children and young people have sustained their SCI from gunshot wounds and ATV (All Terrain Vehicle) accidents. It appears that mechanism of injury, to some extent, is context specific. I am grateful for Australian laws that protect against guns and regulate certain recreational equipment.

- The infrastructure of health care funding influences choice and access to various treatments. A difference was noted amongst insurance, public health and philanthropically funded services in the countries visited.

- Physiotherapists are in a prime position to monitor and promote health during the growing years of a child with SCI, to prescribe suitable specialised equipment and to orchestrate intensive, age appropriate activity programs. The latter may also be an important adjunct to future biological treatments. Skills may be used to facilitate spread of prevention messages and awareness of ramifications of catastrophic injuries.

- I noted that many pertinent questions in my mind were also shared by many clinicians and researchers with whom I interacted. To answer some of these questions, work is already in progress or is yet to be published. For many others the gap remains.
Strategies for intensive activity based programs are also of benefit to other childhood disabilities (e.g. BWSTT and FES cycling for children with cerebral palsy).

SCI in childhood carries a substantial cost in both human and financial terms. It appears that more children survive beyond the initial post injury phase than ever before, especially those with high support needs. Children injured before the age of 16 are estimated to live up to 83% of normal life expectancy (Shavelle et al., 2007). A high demand for health services is anticipated throughout their life span. Like the philosophies of early intervention in general paediatric models, dedication of resources throughout the growing years may ameliorate effects of spinal cord injury, maximise health of the growing body and establish positive lifelong habits during critical stages of development.

Resource allocation in the growing years of SCI service may facilitate the young person’s ability to contribute to society to full potential. Children with SCI are frequently observed to be intelligent and determined individuals with great capacities, with high levels of education and achievement during youth. Alarmingly, US documents show high rates of unemployment (40%) among adults with childhood onset SCI (Anderson & Vogel, 2002). Therefore a two-fold human and financial burden exists.

**Recommendations**

As a result of investigations at a numbers of expert venues abroad for children with acquired spinal cord injury, my expanded recommendations for practices in Australia in physiotherapy and allied health services are that:

- Funding needs to be increased to upgrade resource specialist paediatric services. This will be necessary if services are to provide comprehensive and equitable programs. Government funding and philanthropic support should be priorities.
- Funds should be channelled to development of practical tools and education material for rural and metropolitan service providers and affected families. The internet may be valuable medium for service delivery and communication in addition to direct contact.
- Resources should be dedicated to development of spinal specific group programs. These should enable (1) conduct of intensive activity based and skills training service delivery in a group setting, (2) access to specialised advanced equipment and (3) opportunity for highly beneficial peer interaction.
- Programs should be developed for incidental and / or structured interaction between youths and adults with spinal cord injuries, with the latter assuming a mentoring role.
- Particular research should be focussed on mechanisms of injury in children and youth for subsequent formulation of preventative strategies. The Spinecare Foundation ([http://www.northcott.biz/1-the_spinecare_foundation.php](http://www.northcott.biz/1-the_spinecare_foundation.php)) has recently dedicated funds to seatbelt related research. Current media articles have communicated a need to review motor vehicle child restraint laws in NSW (Marcus, 2010). Other strategies to raise public awareness about traumatic as well as non-traumatic spinal injury would be valuable.
Research initiatives should include children with SCI. Expansion of the current Australian SCIPA Trials (Spinal Cord Injury & Physical Activity, http://www.vni.com.au) to include children may be appropriate. International collaborations to increase subject numbers are desirable. The Australia New Zealand Spinal Cord Injury Network (ANZSCIN) would be an appropriate organisation to oversee such research projects.

Biomedical engineers, surgeons and related professionals should seek to develop next-generation specialised equipment and techniques that impact positively on health in these children and that support spontaneous natural interaction with the others and the environment.

Paediatric specific rehabilitation services and infrastructure are needed in Australia for intensive physical activity programs and development of life skills within a health and wellness model. They need to be well resourced and equipped with the most recent technologies. Staffing levels should be sufficient to support intensive physical activity. This will be important for children with a range of chronic and complex conditions. Children need to be offered further intensive blocks of therapy at regular intervals until maturity.

**Implementation & Dissemination**

Skills and knowledge from the study tour of the Churchill Fellowship will be directly applied to practice of the NSW Paediatric Spinal Outreach Service for immediate benefit to clients. Future increased funding will enable expansion of service throughout NSW and ACT to improve innovative care and access to best practice by children with SCI. The ultimate aim is continuous quality improvement to the current systems in Australia to give these children the best opportunity to grow into productive, satisfied and healthy adults.

In my consultative and educational role in this service, knowledge and skills gained will be disseminated through communications, reports, presentations and service collaboration with rural and community therapists and staff at two Children’s Hospitals in Sydney.

Information gathered will be used as a case in applying for funding from government and private agencies via channels such as my participation in the ‘Exercise and Fitness Equipment working party’ for NSW Lifetime Care and Support Authority.

Other important opportunities for dissemination of knowledge gained on the study tour will be (1) as a member of the Paediatric External Advisory Committee, University of Sydney, a forum to discuss recommended content for undergraduate and physiotherapy Masters degree programs, (2) as clinical supervisor of undergraduate students at my workplace and (3) by attendance at other professional meetings as they arise.
References


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