



# 57<sup>th</sup> ISCoS



## Abstract Book Workshops

The 57th ISCoS Annual Scientific Meeting  
combined with the 25th ANZSCoS ASM

**13 - 15 September 2018**  
**ICC Sydney, Australia**

## Partnering with Regional SCI Consumer Networks

Dr Kim Anderson<sup>1</sup>, Peter Perry<sup>2</sup>, Gunilla Åhrén<sup>3</sup>, Shivjeet Raghav<sup>4</sup>, Jonathan Tang<sup>5</sup>

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Workshop 13, Room C2.2, September 15, 2018, 14:20 - 15:50

People living with spinal cord injury (SCI consumers) are developing consumer networks in multiple regions of the world. A few examples include Europe, Africa, Asia, Australia, and North America. These regional networks tend to be umbrella organizations for multiple smaller, local organizations. For example, the longest standing network, the European SCI Federation (ESCIF), is composed of representatives from 32 separate organizations in 28 countries. Each organization independently can effect change on a local level, but unified under ESCIF they can have a stronger voice on common issues and effect greater change for more people living with SCI. These regional SCI consumer networks can become valuable partners with professionals and professional organizations to impact in an even greater manner clinical care, policy development, research endeavors, and knowledge translation. Not only are SCI consumers necessary partners in dissemination of knowledge about the lived SCI experience to professionals, but they are highly valuable yet underutilized partners in dissemination of knowledge from professionals to consumers. This workshop will focus on describing four of the regional networks and their activities, then developing professional partnerships and identifying shared problems to pursue together.

Learning objectives:

1. Understand how various regional SCI consumer networks formed, operate, and work on projects.
2. Identify resource challenges encountered by consumer networks that are common across different world regions as well as unique to different regions.
3. Identify common topics in clinical care, policy development, research, or knowledge translation that are shared by regional networks and discuss partnerships between the regional networks and with professional organizations to begin working on solutions.

The material presented and discussed in this workshop is suitable for all levels of participants and all audience types. Prior learning or experience is not required for optimal participation.

Outline:

1. Kim Anderson will present the North American SCI Consortium, 15 minutes
2. Peter Perry will present the Australian SCI Alliance, 15 minutes
3. Gunilla Åhrén will present the European SCI Federation, 15 minutes
4. Shivjeet Singh Raghav will present the Asian SCI Network), 15 minutes
5. Discussion with speakers and workshop attendees to identify shared challenges and potential collaborations to begin developing solutions, 30 minutes

The audience will be engaged throughout the workshop. Using universally available internet streaming technology, we will also include a virtual audience of representatives of other regional SCI consumer networks that are not able to attend in person due to physical or financial barriers. The workshop moderator will monitor this streaming link for questions/comments that come in via that mechanism. With this level of technology now available in a cost-effective manner, it is incumbent upon our community to not exclude valuable partners.

## Better Together: Building Capacity for Integrated Knowledge Translation and Consumer Engagement in SCI Research

Mr John Chernesky<sup>1</sup>, Dr Johnny Bourke<sup>2</sup>, Mr John Shepherd<sup>3</sup>, Dr Heather Gainforth<sup>4,5</sup>

<sup>1</sup>*Rick Hansen Institute, Vancouver, Canada,* <sup>2</sup>*Burwood Academy of Independent Living, Christchurch, New Zealand,*

<sup>3</sup>*University of Toronto, Toronto, Canada,* <sup>4</sup>*University of British Columbia Okanagan, Kelowna, Canada,* <sup>5</sup>*International Collaboration on Repair Discoveries (ICORD), Vancouver, Canada*

Workshop 12, Room C2.5, September 15, 2018, 10:50 - 12:20

The gap between research discovery and implementation into practice is estimated to be 17 years. Integrated knowledge translation (IKT) and consumer engagement are approaches that aim to engage consumers as equal partners alongside researchers throughout the research continuum. While these approaches aim to make research more translatable, applicable, and relevant, there is little guidance to help researchers and consumers adopt IKT and consumer engagement methods.

IKT and consumer engagement in research has been shown to increase study enrollment rates and aid researchers in securing funding, designing study protocols, choosing relevant outcomes and translating research into practice. This workshop will provide attendees with an understanding of the steps they can take to engage consumers to add value to their research.

The presenters will cover key issues relating to capacity-building, engagement, and co-design processes for conducting and disseminating research using an IKT or consumer engaged approach, with facilitated discussion leading to recommendations. John Chernesky will provide an overview of the founding philosophy behind inclusion of consumers as research partners. Potential benefits and pitfalls will be discussed, as well as methods to ensure that engagement is conducted in an inclusive and mutually respectful manner. Dr. Johnny Bourke will draw on work conducted in New Zealand to describe different approaches of consumer engagement in research, including building research capacity in consumers, consultation and advisory roles, and partnering to co-produce research projects. Mr. John Shepherd will describe the participatory process used to develop an online peer health coaching platform. The process involved consumers in every role, not only as informants and participants but also as research team members and health coaches, in order to leverage their particular expertise in facing the challenge of living a healthy life with SCI. Finally, Dr. Heather Gainforth will outline lessons-learned from using an IKT approach to conduct and disseminate health promotion research that is relevant and useful to SCI communities. Efforts to improve IKT approaches will be discussed. Specifically, the co-development and implementation of the first IKT guiding principles for conducting and disseminating research in partnership with people with SCI. Throughout the presentations, the audience will be encouraged to ask questions and actively engage in discussion. Participants will be provided with takeaway resources that outline tools and strategies for adopting IKT and consumer engaged techniques.

## Acute Traumatic Cervical Central Cord Syndrome: Management guidelines

Dr Harvinder Chhabra<sup>1</sup>, Dr Rainer Abel<sup>2</sup>, Dr Patrick Kluger<sup>3</sup>, Dr Michael Haak<sup>4</sup>

<sup>1</sup>Indian Spinal Injuries Centre, New Delhi, India, <sup>2</sup>Klinik für Querschnittgelähmte, Bayreuth, Germany, <sup>3</sup>Spine Surgeon (Retired), Erbach, Germany, <sup>4</sup>Geisinger Health System, Danville, USA

Workshop 10, Room C2.2, September 15, 2018, 10:50 - 12:20

Among the incomplete spinal cord syndromes ATCCS is the commonest. Its management principles have been changing since decades even after the establishment of its pathophysiology long ago. There is no high quality evidence supporting a particular line of management for these injuries. In spite of a relatively better prognosis when compared to other incomplete spinal cord syndromes, there are various prognosticating factors for recovery in these injuries. Even though a surgeon or a spine physician decides the management of a particular case, the paramedical staff should also be able to understand their role in both surgical and conservative management protocols, so that they can deliver their duties responsibly. This symposium is designed to update the members on the etiology, pathogenesis, treatment options as well as its evolution and prognostic factors for neurological recovery. These would be discussed threadbare by a team of surgeons of Spine Trauma Study Group of ISCoS using illustrative cases of each type of clinical scenario.

Technical requirements: 1 LCD projector capable of handling input from laptop computers will be needed.

The contributing participants and their role is as below:

1050-1055: Introduction to workshop - H S Chhabra

1055-1102: Etiology, Pathophysiology and natural course - Rainer Abel

1102-1109: Management options - Patrick Kluger

1109-1121: Evolution of management - H S Chhabra

1121-1128: Prognostic factors - Michael Haak

1128-1213: Panel discussion: Role & Timing of surgery in Acute Traumatic Central Cord Syndrome.

Moderator- H S Chhabra. Panelists: Rainer Abel, Patrick Kluger, Michael Haak

1213-1220: Carry home message ( SCS- STSG Consensus statement) - H S Chhabra

## Upper limb reconstructive surgery in SCI – just another part of rehab!

Ms Catherine Cooper<sup>1</sup>, Ms Natasha van Zyl<sup>1</sup>, Ms Claudia Gschwind<sup>2</sup>, Ms Jayne Yeomans<sup>2</sup>

<sup>1</sup>Austin Health, Melbourne, Australia, <sup>2</sup>Royal North Shore Hospital, Sydney, Australia

Workshop 9, Room C2.3, September 15, 2018, 14:20 - 15:50

### \*Learning objectives

1. To understand the role of upper limb reconstructive surgery as a frontline treatment in tetraplegia rehabilitation and to know why, when and how to refer for surgical assessment.
2. To participate in a demonstration clinic with patients presenting for upper limb surgery consultation and to understand the principles of patient/procedure selection after physical examination.
3. To understand the therapist role within the surgery team regarding patient selection, assessment and rehabilitation.

### \*Outline of course

The course will involve presentations and practical demonstration via clinic style assessment of volunteer patients. Material will be delivered by specialist Hand surgeons and therapists from Melbourne and Sydney – the only Australian SCI centres offering surgery.

The broad objective of this course is to normalize upper limb surgery as just one part of the rehabilitation program following cervical SCI.

Presentations will cover the following:

- a. Brief overview of upper limb reconstructive surgery in SCI (20 mins) Natasha van Zyl (Austin Health)  
This presentation will provide a comprehensive summary of current trends in upper limb reconstructive surgery around the world. Natasha and the other speakers will have just returned from the triennial TetraHand conference in Switzerland and will be reporting back on their survey into uptake and opinions around nerve transfers in SCI.  
Surgical techniques and indications for both nerve and tendon transfer procedures will be clearly outlined.
- b. CLINIC demonstration: Including patient selection, assessment and discussion of surgical options (40 mins) Claudia Gschwind (RNS) & Natasha van Zyl (Austin Health) – ALL Team members  
Two or more volunteer patients will be presented to audience as a mock clinic. Depending on numbers attending we may break into smaller groups for enhanced viewing and interaction.  
Detailed physical examination of the upper limb will be demonstrated by the surgeons – highlighting both muscle and nerve donor assessment.  
The discussion to follow clinic will allow understanding of the decision making process around the surgical options that would be presented to a patient.
- c. Therapy role: Post op management and treatment (15 mins) Therapists from Austin Health & Royal North Shore  
Therapists from Melbourne and Sydney will discuss their different models of care and reference telehealth and outreach services. This talk will include a overview of specific assessments and interventions used pre and post surgery.
- d. Questions & discussion (15 mins) All. \* Handouts & references will be provided.

## The importance of trauma, virtue and compassion for clinicians and clients: Psychosocial Issues - EVERYBODY'S business

Ms Annalisa Dezarnaulds<sup>1</sup>, Mr Shane Clifton<sup>2</sup>, Ms Helen Tonkin<sup>3</sup>

<sup>1</sup>Prince Of Wales, Randwick, Sydney, Australia, <sup>2</sup>Alphacrucis College, Parramatta, Sydney, Australia, <sup>3</sup>Royal North Shore Hospital, Spinal Unit, Sydney, Australia

Workshop 1, Parkside 1, September 13, 2018, 09:00 - 10:30

This workshop draws on three distinct but related disciplines to reflect on the impact of personal characteristics on the quality of care provided by clinicians of all types to clients rehabilitating from a SCI. It invites participants to greater self-awareness, and to the realisation that effective care is as much dependent upon the quality of interactions with clients as it is on discipline expertise. As argued by Clinical Psychologist Paul Kennedy, "psychosocial issues are everybody's business," and as such, developing psychosocial competence and confidence is the responsibility of every person in the SCI arena, including clients seeking to flourish as best they can with injury.

Section 1 considers the impact of one's past adverse childhood experiences upon present-day interactions with others in complex and stressful environments. After being introduced to the concept of trauma informed care, it makes space for participants to explore the potential impact of their own past experiences on their present capacity to respond to the difficulties faced working with SCI clients.

Section 2 draws on the virtue tradition and the insights of positive psychology to consider the impact of virtues and vices on effectiveness as a clinician, and as contributing to the resilience of persons with an SCI. It will use a case study to enable participants to explore the meaning and impact of virtue and vice.

Section 3 focuses on the use of mindfulness, compassion and emotion regulation strategies to cultivate emotional balance when working with clients facing grief and loss. The workshop will include a hands-on experience of mindfulness meditation.

## Establishing a Program of Early Intervention Vocational Rehabilitation for People with Newly Acquired Spinal Cord Injury

Dr Gillean Hilton<sup>1,2</sup>, Ms Rachel Harper<sup>3</sup>, Ms Melissa Kelly<sup>4</sup>, Dr Pat Dorsett<sup>5</sup>

<sup>1</sup>Austin Health, Melbourne, Australia, <sup>2</sup>Spinal Research Institute, Melbourne, Australia, <sup>3</sup>Royal Rehab, Sydney, Australia,

<sup>4</sup>Kaleidoscope, Christchurch, New Zealand, <sup>5</sup>Griffith University, Brisbane, Australia

Workshop 11, Room C2.4, September 15, 2018, 10:50 - 12:20

Speaker one will provide an overview of the rationale and evidence for the delivery of vocational rehabilitation to people early after newly acquired SCI. This will include an interactive activity seeking participants to reflect on why work is important for them, and why it could be important for people following SCI. Speaker one will also provide a summary of the known barriers and facilitators of employment for people post injury. Time allocation: 15 minutes

The evolution of EIVR in New Zealand and Australia will be presented by speaker two, as well as what is involved in the current EIVR contexts across these jurisdictions. The driving principles and practice guidelines of EIVR will also be introduced. EIVR practice will be demonstrated through the presentation of a case-study, as well as key thematic findings that have emerged from qualitative research completed with local populations. Finally, speaker two will provide a brief overview of the outcomes that have been achieved in Australia and New Zealand where EIVR programs have been introduced. Time allocation: 15 minutes

In this session, speaker three will lead a discussion about “What is involved in delivering EIVR?”. There will be an opportunity for participants to identify and practice the skills, techniques and strategies understood to be important for engagement around, and delivery of, vocational interventions. Case studies will be presented to assist participants to understand the importance of strategies such as; re-establishing a person’s worker identity, facilitating peer connections, and the use of assistive technology, in promoting hope and possibility around employment. Time allocation: 20 minutes

Speaker four will facilitate discussion and action planning around successful implementation of EIVR in new settings. Participants will be encouraged to identify barriers and facilitators to providing EIVR in their local setting. Following this, participants will be asked to problem solve one action or strategy that they could undertake to help positively shift, or further enhance, the existing culture in their facility/setting around the importance of work after injury. This session will also incorporate a series of Frequently Asked Questions to help demystify the ‘unknowns’ about readiness, capacity and interest in relation to returning to work after SCI. Time allocation: 15 minutes

The final speaker will provide a summary and conclusion to the workshop by reflecting on the importance of collaborating to achieve insights about optimal practice and enhanced employment outcomes for people with SCI. Speaker five will briefly highlight what has been achieved over 10 years of collaboration across Australia and New Zealand. Current and future plans will be to use tools such as the Spinal Collaboration Research Hub – an initiative of the Spinal Research Institute, to assist clinicians and researchers to collaborate. Time allocation: 15 minutes

Q&A/Close: 10 mins

## Spirituality after SCI: What role does it play, and how can we better incorporate it into rehabilitation practice?

Prof Denise Tate<sup>2</sup>, Prof Allen Heinemann<sup>3,4</sup>, Prof Philip Siddall<sup>5,6</sup>, Dr Kate Jones<sup>1</sup>

<sup>1</sup>Royal Rehab, Ryde, Australia, <sup>2</sup>Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, U.S.A., <sup>3</sup>Department of Physical Medicine and Rehabilitation, Feinberg School of Medicine, Northwestern University, Chicago, U.S.A., <sup>4</sup>Center for Rehabilitation Outcomes Research, Shirley Ryan Ability Lab, Chicago, U.S.A., <sup>5</sup>University of Sydney, Sydney, Australia, <sup>6</sup>Pain Management Service, Greenwich Hospital, Greenwich, Australia

Workshop 4, Parkside 1, September 13, 2018, 11:30 - 13:00

Spirituality has received less attention in SCI rehabilitation in comparison to its growing prominence in health outcomes research. Findings have shown a consistent relationship between quality of life (QOL), psychological well-being and spirituality across different patients' groups including SCI. In this workshop we will present research investigating spirituality in the context of SCI and consider the implications of this research for clinical practice. Each presenter will speak for approximately 15 minutes, followed by group discussion.

First, Professor Denise Tate will present the results of an early study which showed similarities and differences in spirituality across patients with SCI and other conditions (cancer, amputation and polio). Group differences were found in terms of life satisfaction, QOL and spiritual well-being. Overall spirituality showed a strong association with both life satisfaction and QOL and it was a significant predictor of life satisfaction among rehabilitation patients.

Professor Allen Heinemann will present the results of recent research examining the association between spiritual well-being, quality of life, and depressive symptoms following SCI. 204 individuals with SCI completed measures of depressive symptomology, spiritual well-being (FACIT-Sp), QOL, and positive and negative affect. Both the Meaning and Peace (M&P), and Faith scales of the FACIT-Sp predicted QOL though only the M&P scale was an independent predictor of depressive symptoms. These findings indicated that spirituality is associated strongly with QOL and severity of depressive symptoms.

Professor Philip Siddall will present the results of a study which sought to determine whether SCI and pain have an impact on spiritual well-being, and whether there is an association between spiritual well-being and measures of pain and psychological function. Questionnaires evaluating pain, psychological and spiritual well-being were administered to a group with a SCI (n=53) and a group without a SCI (n=37). There was a moderate but significant negative correlation between spiritual well-being and pain intensity. There was also a strong and significant negative correlation between depression and spiritual well-being and a strong and significant positive correlation between spiritual well-being and both pain self-efficacy and satisfaction with life.

Dr Kate Jones will present the qualitative results of her doctoral study, on the relationship between spirituality and family resilience after SCI. Various sources of spirituality were identified from longitudinal interviews with family dyads, including religious faith, the natural world, connectedness with others, and oneself. These sources of spirituality were identified as contributing towards hope, gratitude, and deepening connectedness with others, all of which assisted families to move forward with strength and resilience. A model outlining these results will be presented.

The findings of these four studies suggest that spirituality is an important component of long-term rehabilitation, and clinicians should assess spirituality as part of a broader psychological and social assessment to inform treatment. Following the presentations, we will facilitate a group discussion on how spirituality could be better integrated into clinical practice. During this discussion we will consider barriers and enablers relating to such integration. There will be opportunity to exchange innovative practice examples and ideas.

## Abdominal functional Electrical Stimulation to improve respiratory function in spinal cord injury

Dr Euan J McCaughey<sup>1</sup>, Prof Jane B Butler<sup>1</sup>, Dr Bonsan Bonne Lee<sup>1,2</sup>, Dr Claire L Boswell-Ruys<sup>1,2</sup>

<sup>1</sup>Neuroscience Research Australia, Randwick, Australia, <sup>2</sup>Spinal Injuries Unit, Prince of Wales Hospital, Randwick, Australia

Workshop 5, Room C2.1, September 13, 2018, 11:30 - 13:00

The abdominal muscles are one of the key muscles of respiration, with a contraction of these muscles vital to achieve an effective forced exhalation or cough. Surface functional electrical stimulation of the abdominal muscles, termed Abdominal Functional Electrical Stimulation (Abdominal FES), can be used to make the abdominal muscles contract, even when 'paralysed'. As world leaders in Abdominal FES research, over the past 10 years we have shown through seven clinical studies (representing over 50% of all Abdominal FES studies in spinal injury; e.g.<sup>1,2</sup>) that the repeated application of Abdominal FES improves the respiratory function of people with tetraplegia. Specifically, our meta-analysis demonstrated that the application of Abdominal FES causes an immediate improvement in Cough Peak Flow.<sup>3</sup> Additionally, the repeated application of Abdominal FES over a number of weeks, termed Abdominal FES training, was shown to improve unassisted vital capacity, forced vital capacity and peak expiratory flow.<sup>3</sup> Despite these positive results, clinical uptake of Abdominal FES remains low.

This workshop aims to provide participants with a better understanding of how Abdominal FES works, when it should be used, and how to apply it. The audience will be encouraged to ask questions and engage in the issues discussed, before taking part in an interactive demonstration. The ideas and discussions elicited during the workshop will inform future research projects and clinical activities.

### Topics to be covered

Topics to be covered include:

- 1) What is Abdominal FES and how does it work?
- 2) Who should Abdominal FES be used with, and when should it be applied?
- 3) How do I apply Abdominal FES to a spinal cord injured patient?

### Target audience

This workshop will be of relevance to those involved in:

- the acute care of people with tetraplegia
- hospital based care and rehabilitation of people with tetraplegia
- caring for those with tetraplegia in the community

### Outline

- 1) The principals of Abdominal FES – 10 minutes (Dr E McCaughey)
- 2) Findings from previous clinical trials – 15 minutes (Prof J Butler and Dr B Lee)
- 3) Lessons learned from previous clinical trials – 10 minutes (Dr C Boswell-Ruys)
- 4) future pathways for Abdominal FES- 10 minutes (Dr E McCaughey)
- 5) Interactive discussion – 10 minutes (chair Prof J Butler)
- 6) Hands on demonstration of how to apply Abdominal FES – 30 minutes (all presenters)
- 7) Wrap up and overall summary – 5 minutes (Dr E McCaughey)

- <sup>1</sup>. Lee BB, Boswell-Ruys C, Butler JE, Gandevia SC. Surface functional electrical stimulation of the abdominal muscles to enhance cough and assist tracheostomy decannulation after high-level spinal cord injury. *J Spinal Cord Med* 2008; 31: 78-82.
- <sup>2</sup>. Butler JE, Lim J, Gorman RB, et al. Posterolateral surface electrical stimulation of abdominal expiratory muscles to enhance cough in spinal cord injury. *Neurorehabil Neural Repair* 2011; 25: 158-67.
- <sup>3</sup>. McCaughey EJ, Borotkanics RJ, Gollee H, Folz RJ, McLachlan AJ. Abdominal functional electrical stimulation to improve respiratory function after spinal cord injury: a systematic review and meta-analysis. *Spinal Cord* 2016; 54: 628-39.

## WHO and ISCoS Collaboration for Strengthening SCI rehabilitation in low and middle-income countries

Prof James Middleton<sup>1</sup>, Ms Pauline Kleinitz<sup>2</sup>, Dr Pratima Gajraj<sup>3</sup>, Dr Ron Reeves<sup>4</sup>, Ms Kathryn Dwyer<sup>5</sup>

<sup>1</sup>Chair, ISCoS External Relations Committee, Sydney, Australia, <sup>2</sup>Rehabilitation Programme, World Health Organisation, Geneva, Switzerland, <sup>3</sup>Ministry of Health, , Fiji, <sup>4</sup>Mayo Clinic, Rochester, USA, <sup>5</sup>Home Action Team, Laura Fergusson Trust (Canterbury), Christchurch, New Zealand

Workshop 3, Room C2.3, September 13, 2018, 09:00 - 10:30

This workshop is a collaborative initiative between ISCoS and the World Health Organisation that will outline WHO strategic approaches for strengthening rehabilitation in health services in low-middle income countries and provide three examples of innovative practices and working together to develop SCI services in the Western Pacific Region for discussion. Presentations will be the following:

(i) WHO Rehab 2030 Call for Action and ISCoS-WHO Collaboration Plan for Strengthening SCI Rehabilitation with Health Systems (Pauline Kleinitz, 20 minutes)

Pauline Kleinitz will first introduce the workshop, providing an overview of the WHO Rehab 2030 Call for Action and its key messages, along with WHO Support Package for Rehabilitation to assist governments in strengthening the health system to provide quality rehabilitation services. The Support Package guides governments through a four-step process of rehabilitation system assessment, strategic planning, establishing a monitoring framework with evaluation and review processes, as well as implementation. ISCoS and WHO working together to provide real support to countries through strengthening SCI rehabilitation is seen as a catalyst/enabler to improving rehabilitation systems in general for all people with complex needs.

(ii) Developing a rehabilitation strategic plan and mobile Outreach program for people with SCI in Fiji (Pratima Gajraj, 15 minutes)

Dr Gajraj will describe work in Fiji and how the WHO has been supporting the Fiji Ministry of Health to develop a rehabilitation strategic plan, as well as a Mobile Outreach programme targeting people with SCI. The impact of high level strategic planning within health will be discussed, as well as the development of rehabilitation programmes that collect data and demonstrate results.

(ii) ISCoS and WHO supported SCI training in Mongolia (Ron Reeves, 15 minutes)

Dr Reeves will focus on the role of education for capacity-building using the recent example of a successful collaboration in Mongolia between ISCoS, WHO and Ministry of Health delivering a 3-day multidisciplinary SCI Seminar to health professionals in Ulaan Baatar in October 2017. He will highlight challenges, such as language, materials, cross-cultural translation, as well as progress on planning to strengthen the rehabilitation sector in Mongolia and increase quality and coverage of SCI services.

(iv) Developing community-based SCI services for people with SCI in Samoa and Tonga (Kathryn Dwyer, 15 minutes)

Kathryn will overview development of SCI services in Samoa and Tonga, highlighting the different models of service provision that have been used with collaborative input of interdisciplinary healthcare professionals from Samoa and New Zealand with volunteers to provide treatment, therapy, training, equipment and housing modifications. The challenge of developing this service and integrating what is currently a community-based and largely volunteer driven SCI service into the national health services in Samoa will be discussed.

(v) Interactive Discussion (All speakers & workshop participants, 20 minutes)

The audience and panel of speakers will engage in facilitated discussion, identifying approaches that have worked well and what characteristics and potential commonality exists between them. Future opportunities for collaboration in the Western Pacific and other regions will be explored to inform planning and ongoing development activities between ISCoS and WHO.

## Design and delivery of appropriate and sustainable SCI healthcare and rehabilitation services in low resourced settings

Mr Stephen Muldoon<sup>1</sup>, Prof Lisa Harvey<sup>2</sup>, Miss Fiona Stephenson<sup>1</sup>, Dr Ellen Merete Hagen<sup>3</sup>

<sup>1</sup>Livability, Enniskillen, United Kingdom, <sup>2</sup>John Walsh Centre for Rehabilitation Research, Sydney, Australia, <sup>3</sup>1National Hospital for Neurology and Neurosurgery, London, United Kingdom

Workshop 14, Room C2.4, September 15, 2018, 14:20 - 15:50

International Perspectives on Spinal Cord Injury (IPSCI) highlights that SCI has historically been associated with very high mortality rates and in many countries SCI remains a terminal condition. WHO highlights that people with disability, particularly in low-mid income countries (LMIC), experience poorer health outcomes and face widespread barriers in accessing services such as healthcare and rehabilitation. Barriers include inadequate legislation, policies and strategies, lack of service provision, negative attitudes, discrimination and inadequate funding. Half of all disabled people cannot afford necessary healthcare and are 50% more likely to suffer catastrophic health expenditure. Rehabilitation in Health Systems (WHO) states that strengthening service delivery and ensuring it is adequately financed, is fundamental to ensuring that rehabilitation is available and affordable to those who need it.

While challenges remain there are many examples where the quality and delivery of services for people with SCI have been strengthened. Drawing on examples and applying a “systems strengthening approach” this workshop will present and discuss strategies that can strengthen and increase access to appropriate and sustainable SCI services in LMICs.

### Structure:

1. To provide an overview of the Health Systems Strengthening approach and relevance to the development and delivery of SCI Services in LMICs.
2. Presentations to demonstrate practical examples and case studies that have supported the development and delivery of sustainable SCI services in LMICs:
  - **Service Delivery:** To present the case study of the Spinal Injury Rehabilitation Centre (SIRC) Nepal. Starting in 2002 with 2 patients, 2 staff and \$10,000 this centre has evolved to become a fully fledged 75-bedded specialist rehabilitation facility with proven capacity to respond to a sudden onset humanitarian disaster. To discuss factors associated with growth and sustainability, the outcomes being achieved and challenges that remain
  - **Human Resource Development:** To present and discuss outcomes arising from ISCoS Educational activities aimed at strengthening organizational, technical and human resource capacity within rehabilitation systems in low resourced settings. To explore the benefits and added value of collaboration and partnership in increasing coverage of SCI education.
  - **Data Collection and Research:** To present examples of effective international partnership and collaboration models for the design and implementation of research. Present case studies of ongoing research projects and how these can help identify gaps and influence the design and delivery of practical and low cost SCI service provision in resource poor environments

- Leadership and Governance: To present examples and discuss the sustainable development and delivery of SCI service delivery in the context of National: Legislation; Policy; and Implementation Strategies

3. A facilitated discussion to allow panelists and audience to discuss and make recommendations on how to support a continued increase in the coverage and quality of appropriate and sustainable SCI services in resource poor environments.

Topic/Presentation Speaker: Duration (minutes)

Health Systems Strengthening Approach Stephen Muldoon 12  
Service Delivery Fiona Stephenson 12  
Human Resource and Capacity Development Ellen Merete Hagen 12  
Data Collection and Research Lisa Harvey 12  
Legislation, Policy and Implementation Strategies Stephen Muldoon 12  
Facilitated Discussion 30  
Total: 90

## "A" is for "Airway" - the ABCs of Airway Clearance in Spinal Cord Injury

Dr Colleen O'Connell<sup>1,2</sup>, Prof David Berlowitz<sup>3,4</sup>, Nicole Sheers<sup>3,4</sup>, Miss Marnie Graco<sup>3,4</sup>

<sup>1</sup>Dalhousie University Faculty of Medicine, Fredericton, Canada, <sup>2</sup>Stan Cassidy Centre for Rehabilitation, Fredericton, Canada, <sup>3</sup>University of Melbourne, Melbourne, Australia, <sup>4</sup>Institute for Breathing and Sleep, Austin Health, Melbourne, Australia

Workshop 2, Room C2.2, September 13, 2018, 09:00 - 10:30

Pulmonary complications as a result of impaired respiratory muscle strength are among leading causes of acute and long term morbidity and mortality in persons with spinal cord injury (SCI). An effective cough is reported to require a peak cough flow (PCF) of at least 160 L/min in order to mobilize and clear secretions. Impaired airway clearance, primarily as a result of expiratory muscle paralysis increases risks for atelectasis, pneumonias, reduced ventilation and respiratory failure. Despite the availability of published guidelines and relatively simple techniques available for management, there remains poor uptake in both inpatient and community settings for people with spinal cord injury who are at risk. For example, a recent mixed methods study revealed low knowledge and use of such strategies among experts in SCI and neuromuscular disease in Canada. Experts in Australia suggest similar findings in their experiences.

In this workshop, presenters will summarize the rationale and evidence supporting the need for airway clearance assessment and treatment in SCI, and introduce an algorithm for evaluation and treatment of airway clearance impairment in SCI. Instruction on how to perform basic measures of respiratory muscle strength and cough effectiveness will lead into demonstration of practical and accessible airway clearance therapies. Facilitated discussion on barriers and facilitators to best practice implementation will help participants identify opportunities for practice change, with the goal of each participant having a personal take-away action plan.

1. Overview of pulmonary complications in SCI and rationale for airway clearance management, highlighting current state of best practice implementation – 10 min, O'Connell
2. Introduction to airway clearance, assessment measures and screening algorithm for treatment; how, when and what to do at various levels of impairment– 15 min, Berlowitz
3. Illustration of inspiratory and expiratory support in airway clearance, including lung volume recruitment, manual assisted cough, maximum insufflation capacity-vital capacity measurement (MIC-VC) and mechanical insufflation/exsufflation in practice – Sheers, 20 min
4. Demonstration and practice of peak cough flow measurement and lung volume recruitment, MIC-VC difference with modified ambu-bag – 30 min (all speakers)
5. Group discussion on barriers, facilitators and take away action plans – 15 min, Graco

## SCI Clinical Research Interactive Workshop: Developing Practical Tools for Global Research Collaborations in a Time Poor World

Dr Keith Hayes<sup>1</sup>, Jane Hsieh<sup>2</sup>, A.Prof Doug Brown<sup>3</sup>, Emma Peleg<sup>3</sup>

<sup>1</sup>Ontario Neurotrauma Foundation, Toronto, Canada, <sup>2</sup>Wings for Life, Toronto, Canada, <sup>3</sup>Spinal Research Institute, Kew, Australia

Workshop 7, Parkside 1, September 13, 2018, 16:00 - 17:30

International multi-centre research collaboration has long been a discussion in the field (Barrable et al, 2014; Butler et al, 2008; Richards JS, 2002) and achieved more focus at ISCoS Scientific Meetings. Both early career and established researchers see international collaboration as a pathway to fast-track the translation of SCI research into practice; ultimately making a global impact in SCI care. The facilitation of international collaboration is currently limited to personal and institutional connections. For many specialists working in low-income countries, the lack of an academic program, mentors, and funding further limit collaborative efforts. Platforms that enable communication and sharing of research materials have been identified as important enablers for researchers to collaborate internationally ([http://www.rickhanseninstitute.org/images/stories/Praxis2016/Action\\_Plan/Praxis\\_Action\\_Plan\\_FINAL.pdf](http://www.rickhanseninstitute.org/images/stories/Praxis2016/Action_Plan/Praxis_Action_Plan_FINAL.pdf)). The SRI's Spinal Cord Research Hub (SCoRH) will be the first assistive technology of its kind designed exclusively for the SCI field, enabling SCI researchers to connect and collaborate with colleagues, other clinicians and clinical trial participants in the near future, in a secure online setting.

This workshop is an active outcome of previous collaboration workshops and an important next step in developing collaborative networks in SCI research.

Delegates are recommended to bring personal ipad or laptop to this session to enable active participation in the discussion groups.

Pre-reading documents are encouraged to ensure participants are best prepared to contribute and move the workshop forward and will be available here:

<https://www.thesri.org/conferences>

Chair: Keith Hayes

- Speaker 1: Dr Keith Hayes

Developments of collaborative research to date and anticipated outcomes for this workshop

10 min

- Speaker 2: Jane Hsieh

SCI Trials Toolkit (SCITT) and Guidance documents for SCI research - Spinal Trials Understanding, Design and Implementation (STUDI)

10 min

- Speaker 3: A/Prof Doug Brown

A Collaboration Tool to Support SCI Research – Spinal Cord Research Hub (SCoRH)

Introduce the SCoRH platform and the supporting service

10 min

- Speaker 4: Emma Peleg

Spinal Cord Research Hub (SCoRH)

Live demonstration of SCoRH as a supported communication tool for collaboration in SCI research

10 min

- Active break out session

45 min

- Summary and Conclusion

10 min

Demonstration of an online website, Spinal Cord Research Hub (SCoRH) will be required as part of the session. Access to the internet, keyboard and touch pad/mouse to enable manoeuvre around website and projection onto the room screen will be required. Set up time will be required approximately 30 minutes prior to the session.

Delegates will require access to conference facility Wi-Fi for this session.

Sponsoring Organisations

The Spinal Research Institute, the Rick Hansen Institute, Ontario Neurotrauma Foundation and Wings for Life.

References:

Barrable et al Model for bridging the translational “valleys of death” in spinal cord injury research. *J of Healthcare Leadership*. 2014;6 15-27

Butler D. Translational research: crossing the valley of death. *Nature*. 2008; 453(7197): 840-842

Richards JS. Collaborative research in the model spinal cord injury systems: process and outcomes. *J Spinal Cord Med*. 2002; 25(4): 331–334.

## Clinical assessment of the autonomic nervous system

Dr Marcalee Alexander<sup>1</sup>, Dr Jean-Gabriel Previnaire<sup>3</sup>, **Prof Andrei Krassioukov**<sup>2</sup>, Dr Ellen Merete Hagen<sup>4</sup>

<sup>1</sup>University of Alabama, Birmingham, USA, <sup>2</sup>University of British Columbia, , Canada, <sup>3</sup>Centre Calvé, Fondation Hopale, Berck sur Mer, France, <sup>4</sup>Institute of Neurology, UCL, London, UK

Workshop 8, Room C2.1, September 13, 2018, 16:00 - 17:30

Marcalee Alexander (15 minutes)

- o Anatomy and function of the autonomic nervous system
- o Neural control of the cardiovascular and the sudomotor systems
- o Autonomic dysreflexia and orthostatic hypotension
- o The International standards to document remaining autonomic function after spinal cord injury (ISAFSCI)
- o The upcoming revision of the ISAFSCI

Jean-Gabriel Previnaire (15 minutes)

Bedside tests will be presented with special attention on how to best perform them

- o Skin axon reflexes (vasomotor reflex)
- o Sudomotor reflexes
- o Pilomotor reflexes
- o Scrotal and dartos reflexes
- o Pupillary reflexes

Andrei Krassioukov (15 minutes)

- o Head-up and sit-up tilt tests
- o Heart rate variability
- o Respiratory tests (deep breathing)
- o Sympathetic skin response
- o Pressure tests (cold...)

Ellen Merete Hagen (15 minutes)

- o Significance and relevance of bedside vs. clinical tests:
- o Interest of single tests vs. battery of tests
- o Autonomic testing in the acute vs. chronic phase
- o Severity of autonomic lesions (complete or incomplete lesions)
- o Recommendations for practice

## Peer-led Community Integration Interventions

Miss Lucy Robinson<sup>1,2</sup>, Dr Gillean Hilton<sup>3</sup>, Mrs Debra Edmonds<sup>4</sup>, Mr James Hektner<sup>5</sup>

<sup>1</sup>NSIC, Stoke Mandeville Hospital, Aylesbury, United Kingdom, <sup>2</sup>Back Up Trust, London, United Kingdom, <sup>3</sup>Victorian Spinal Cord Service – Austin Health, Victoria, Australia, <sup>4</sup>New Zealand Spinal Trust, Burwood, New Zealand, <sup>5</sup>Accessible Okanagan, Okanagan, Canada

Workshop 6, Room C2.2, September 13, 2018, 11:30 - 13:00

### INTRODUCTION:

The introduction of the workshop will provide a brief history of consumer/people with lived experience involvement in ISCoS, and the evidence for peer-led interventions as part of spinal cord injury management programs. The introduction will also emphasise where there are ongoing opportunities to strengthen practice in this field, and the importance of using robust research and evaluation frameworks to inform these practice changes. 10 minutes

### WHEN IS PEER-LED INTERVENTION MOST EFFECTIVE?

In 2014 CARF International published standards on the delivery of peer support services. Drawing on extensive work in the NHS and with Back Up Trust in the UK and other international peer-led programs, Lucy Robinson will present insights around implementing these standards in her own practice. Lucy will then lead an interactive activity focused on assisting participants to understand when peer-led intervention is most effective and to identify opportunities for implementation in their local settings. 20 minutes

### THE UPS AND DOWNS OF SOCIAL MEDIA

Increasingly easy access to social media platforms for users from across different socioeconomic backgrounds presents plentiful opportunities for people with lived experience of SCI to connect with others. James Hektner will reflect on the benefits of social media, such as the ability to connect with people in rural and low-cost settings, as well as the pitfalls, and strategies to optimise uptake and appropriate usage. 10 minutes

### EVALUATION OF PEER-LED INTERVENTION

Peer-led interventions can be delivered in hospital or community based settings, and are often provided by not for profit organisations. There are therefore inherent challenges in conducting appropriate research and evaluation of peer-led interventions due to the variety and diversity of audiences that the results may be of interest to. This session will offer examples of how some organisations have commissioned research and evaluation to monitor inputs and outcomes of programs. This information has then been used to ensure programs are meeting the need of the local SCI community and are providing value for money to program sponsors. Debra will lead an interactive activity where participants will be asked to problem solve ways of undertaking research and evaluation, including possible opportunities for collaboration across universities and the not for profit sector. 25 minutes

### THE IMPORTANCE OF COLLABORATION

Extensive planning, open communication, commitment to the value of peer-led intervention and a willingness to collaborate will see the delivery of a peer-led residential course conducted in the week preceding ISCoS. Based on the documented components of 'active rehabilitation', and an established course methodology, Lucy Robinson and Back Up Trust from the UK will work with Royal Rehab in Sydney to implement a 5 day 'skills for independence' course. This session, led by Gillean Hilton will reflect on what

was involved in setting up and evaluating the peer led course. Drawing on this initiative Gillean will lead a group interactive activity to identify opportunities for future collaborative efforts in the area of peer-led interventions. 20 minutes

#### SUMMARY

Key discussion points from the workshop will be summarised and audience reflections welcomed. 5 minutes

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