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ANNUAL SCIENTIFIC MEETING

**WORKSHOPS
ABSTRACT BOOK**

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SCI-High Project: Measuring quality of rehabilitation from hospital to home

Dr Cathy Craven¹, Dr. Colleen O'Connell², Farnoosh Farahani¹

¹Neural Engineering & Therapeutics Team, KITE, Toronto Rehab – University Health Network, Toronto, Canada, ²Stan Cassidy Centre for Rehabilitation, Fredericton, Canada

Introduction: Health quality indicators (i.e. measures) are key to understanding the quality of care and identifying actionable opportunities for improving health system performance. Although indicator development is advancing in stroke rehabilitation, there is still a paucity of indicators for spinal cord injury (SCI) rehabilitation. Current Canadian data is restricted to impairment, length of stay and Functional Independence Measure Efficacy. The aim of the SCI Rehabilitation Care High Performance Indicators (SCI-High) project is to establish a framework of structure, process and outcome indicators within 11 domains of SCI rehabilitation care to improve rehabilitation care from inpatient admission to 18 months post-rehab admission. National Working Groups were formed to select and develop indicators relevant to each Domain. Indicators were divided in structure (infrastructure characteristics), process (processes of care) and outcome (effects of care). Potential indicators were piloted at participating sites to assess the feasibility, inform Standard Operating Procedure (SOP) development and formulation of preliminary benchmarks. Six domains of care - Emotional Well-Being, Sexual Health, Tissue Integrity, Urinary Tract Infection, Walking, and Wheeled Mobility - were prioritized for implementation at five rehabilitation centres in Ontario, Canada.

Workshop aims:

Six domains of rehabilitation will be discussed in terms of: 1) domain prioritization process; 2) indicator development; 3) early deployment; and 4) next steps. Dr. Craven will provide an overview of the general SCI-High Project and primary objectives. Ms. Farnoosh Farahani will present the domain prioritization process for the six domains currently being implemented in Ontario (Emotional Well-Being, Sexual Health, Tissue Integrity, Urinary Tract Infection, Walking, and Wheeled Mobility) and the indicator selection methodology. Dr. O'Connell will discuss in details and present results of the Sexual Health Domain. Other examples including the Emotional Well-Being and Urinary Tract Health domains aligned with the ISCOS 2019 themes will be presented. Finally, the panelists will discuss the implementation process and linkage of the indicators with Accreditation Canada and Health Standards Organization SCI standards.

Workshop learnings: Attendees will become familiar with different types of quality indicators, processes for selection and development of indicators, indicator content, and their associated benchmarks. Participants will review in details select domains that are transferable to other centres internationally. The final goal is to enlighten how quality indicators can be used to drive best-practices implementation and delivery of optimal care.

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Psychosocial Skills Development Workshop:

Psychosocial care is ‘everyone’s business’- enhancing knowledge and skills for everyday practice using the **Emotional Wellbeing Toolkit: A Clinician’s Guide to Working with Spinal Cord Injury.**

Ms Annalisa Dezarnaulds¹, Ms Helen Tonkin

¹*Prince Of Wales Hospital, Sydney, Australia*

Introduction:

Spinal Cord injury is a complex condition from a medical, physical and psychological perspective. The NSW State Spinal Cord Injury Service (SSCIS) in Australia established a Psychosocial Strategy following Professor Paul Kennedy’s visit to Australia in 2006 to advocate for the importance of psychosocial issues for those adjusting to and living with a spinal cord injury. Professor Kennedy defined the importance of psychosocial interventions for those adjusting to, and living with, a spinal cord injury (SCI). Most notably, he suggested that appropriate, confident and consistent psychosocial care was ‘everyone’s business’, not only the domain of psychology, social work or psychiatry.

Incorporating the Model of Adjustment (Middleton & Craig, 2008; Craig, Tran & Middleton, 2017), and with the use of a case presentation, participants in small groups will be asked to identify psychosocial issues, answer questions and formulate an intervention plan using the Emotional Wellbeing Toolkit*. Participants are then be asked to identify their use of Brief Clinical Tools, embedded in the Toolkit, that would be used when engaging with this patient, supporting consistent practice across all sectors. In addition, helpful and un-help ways of engaging around challenging behaviours will be demonstrated using ‘role plays’ and then practiced in small groups.

The clinical utility of The Emotional Wellbeing Toolkit, within the context of the skills building workshop, has been assessed extremely positively and considered a valuable and welcome resource by nurses, doctors and allied health clinicians alike from all around Australia. Workshops have thus far been offered to the attendees of the ‘Spinal Cord Injury Core Course’ training (RNSH, Sydney 2014-2019); icare Life Time Care and Support (the NSW Government compensation support for victims of catastrophic motor vehicle injury); non-government spinal cord injury peak bodies - Spinal Cord Injuries Australia and Paraquad Australia; in-service for new graduate nursing programs in both RNSH and POW hospitals and in-service training to Occupational Therapy and Social Work Departments.

*The Emotional Wellbeing Toolkit is an evidence-based resource containing validated and standardised tools. The Toolkit was developed for all staff to improve understanding of the importance of Person-Centered and Trauma Informed Care within the Spinal Cord Injury acute, rehabilitation and community integration settings, and screen for suspected psychological difficulties, recognising the critical role they play in assisting patients in crises and with long-term adjustment.

Middleton J, Craig A. Psychological issues associated with spinal cord injury and its management (Chapter 1). In A Craig and Y Tran (Eds.). Psychological dynamics associated with spinal cord injury rehabilitation: New directions and best evidence. New York: Nova Science Publishers Inc., 2008 (ISBN: 978-1-60456-996-4). p. 3-53.

Craig A, Tran Y, Middleton J. Theory of adjustment following severe neurological injury: evidence supporting the Spinal Cord Injury Adjustment Model. (Chapter 3). In Andres Costa and Eugenio Villalba (Eds.) Horizons in Neuroscience Research Volume 29. New York: Nova Science Publishers. Copyright 2017 Nova Science Publishers, Inc., New York. ISBN: 978-1-53610-816-3. ISSN: 2159-113X. p. 117-139.

The International Spinal Cord Injury Physical Therapy - Occupational Therapy Basic Data Set: Rationale, Evidence, and Vetting

Prof Edelle Field-Fote¹, Prof Kimberley Anderson², Prof Lisa Harvey³, Prof Marcel Post⁴

¹Shepherd Center, Atlanta,, United States, ²Case Western Reserve University, Cleveland,, United States, ³University of Sydney, Sydney,, Australia, ⁴Hoogstraat Rehabilitation, Utrecht, Netherlands

Nearly all interventional trials use the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) as the primary or secondary endpoint of neurologic recovery. Since physical and occupational therapies (PT-OT) promote use-dependent plasticity that has the potential to impact the ISNCSCI scores, it is important to consider the influence of these therapies when provided in conjunction with clinical interventional trials. To facilitate efficient tracking of therapy content and dose (time), an international workgroup developed a standardized collection and reporting tool and accompanying syllabus: The International Spinal Cord Injury PT-OT Basic Data Set. During the process of developing the data set, the workgroup solicited input from numerous sources including from PTs and OTs at the institutions where the workgroup members are affiliated, and at the 2017 ISCoS meeting. Taking all feedback into consideration, the workgroup modified the data set over multiple iterations. By the time of the ISCoS 2019 meeting, the data set is expected to be at the stage of development where it has received approval from the ISCoS Data Set Committee, ASIA Board of Directors, and ISCoS Scientific Committee and will be posted for public comment. As the intent of the PT-OT Basic Data Set is to provide a uniform mechanism to efficiently track the content and dosing of PT-OT sessions without undue burden on the therapist, international audience feedback about how the data set and the syllabus meet this goal is invaluable. This workshop will be an interactive session to present the updated data set and provide a forum for discussion. Participation will be encouraged throughout the workshop, and feedback will be incorporated into the dataset refinement process.

Outline:

- 1) Evidence for the influence of PT-OT interventions on strength–20 Mins (Lisa Harvey)
- 2) Development of the The International Spinal Cord Injury PT-OT Data Set–20 Mins (Kim Anderson)
- 3) Using the data set in the clinic–15 Mins (Edelle Field-Fote)
- 4) Vetting process to date and plans for reliability/validity testing–15 Mins (Marcel Post)
- 5) Stakeholder feedback–25 Mins

Clinical Trial Design: Can adaptive SCI trial designs accelerate acquisition of evidence to guide practice?

MD, PhD, FACS, FRCS James Guest¹, Professor, Dr. Armin Curt², PT, PhD, FAPTA Edee Field-Fote³, MD, PhD Zev Rymer⁴

¹Miami Project, University of Miami, Miami, USA, ²Der Balgrist, University of Zurich, Zurich, Switzerland, ³Shepherd Center, Emory University, Georgia Institute of Technology, Atlanta, USA, ⁴Shirley Ryan Ability Lab, Northwestern University, Chicago, USA

Overall Course Objective: Explore and the pros and cons of adaptive design approaches relative to traditional clinical trial designs in three research areas: Drugs/biologics, rehabilitation, physiological manipulation (intermittent hypoxia).

Learning Objectives:

1. Describe the current, traditional design of three current trials.
2. Present alternative adaptive trial design approaches.
3. Debate the pros and cons of traditional vs. adaptive designs.

Synopsis:

Medical evidence drives changes in practice through the scientific evaluation of emerging therapeutics. Traditional trial designs such as prospective randomized (1:1) controlled trials remain the “gold standard” in clinical research. Such trials are typically expensive, require several years to generate conclusions, and often have limited generalizability. Adaptive designs which incorporate accruing data can evolve based on probabilities determined during the study. Such designs are widely used in other medical fields such as cancer therapeutics. In the United States, the Food and Drug Administration has provided detailed assessments of the merits and limitations of adaptive trial designs that seek to define those who benefit and those who do not and subsequently focus only on responders. In this interactive workshop, we will present a brief summary of three ongoing clinical trials in the areas of drug, rehabilitation and physiologic manipulation (e.g. intermittent hypoxia). We will then discuss and debate how adaptive features could be integrated into these designs to improve their efficiency. The key considerations that favor or discourage these approaches will then be debated from the perspective of sponsors, regulators, statisticians and clinical trialists. We will wrap up with audience discussion on incorporation of alternative designs in future trials.

This workshop is sponsored by SCOPE (Spinal Cord Partnership Endeavors) and AO Spine.

Proposed agenda:

1. Introduction and workshop outline – 5 mins. (James Guest)
2. Traditional drug trial design and adaptive alternative with pro/con debate – 20 mins.
Armin Curt/James Guest
3. Traditional rehabilitation trial design and adaptive alternative with pro/con debate – 20 mins.
Edelle Field-Fote/James Guest
4. Intermittent hypoxia trial design and adaptive alternative with pro/con debate – 20 mins. Zev Rymer/James Guest
5. Audience discussion – 25 mins.

Moderator: James Guest, Panel Participants: Armin Curt, Edelle Field Fote, Zev Rymer

Evaluating and Treating persons with NBD (neurogenic bowel dysfunction)

Dr Steven Kirshblum, Dr Klans Krogh, Dr Anton Emmanuel

¹*Kessler Institute for Rehabilitation, West Orange, United States*

Outline of Workshop (Total time = 90 minutes):

Speaker 1: Introduction (15 minutes):

- Importance and impact of NBD in SCI
- Limitations to current assessment tools available

Speaker 2: MENTOR (Monitoring Efficacy of Neurogenic bowel Treatment On Response) tool description (20 minutes)

- Development of and results of an international collaborative trial of the newly developed assessment tool

Speaker 3: Interactive case presentations using an audience response system (20 minutes)

Speaker 4: Advanced management techniques for NBD (20 minutes)

Questions and Answers (15 minutes)

No advanced set up will be needed.

Handouts including the MENTOR toolkit will be prepared and available for participants. No additional costs or set up will be required.

Neurogenic Bowel Dysfunction (NBD) is an important consequence of spinal cord injury (SCI) that has a significant impact on the quality of life. The lack of validated tools to monitor the efficacy of treatment makes it more difficult for clinicians and patients to know when their treatment is most appropriate. This can lead to a lack of attention to the problem(s) by the healthcare professional and sustained suffering by the patient.

The first section of the workshop will present key aspects in treatment of NBD for persons with SCI. The second will review the development and results of an international collaborative trial of the newly developed assessment tool, MENTOR, that was developed based on bowel symptoms and patients' subjective perception of their bowel function. The level of concordance between the MENTOR tool and clinical decision by the international panel of experienced clinicians specializing in NBD will be described as well as the very high degree of acceptance and user-friendliness of the tool as graded by persons with NBD.

The next sections of this workshop will include an interactive discussion with the audience (using an audience response system), reviewing specific patient presentations using the MENTOR tool, as well as discussing treatment options. Finally, advanced techniques for management of NBD will be discussed.

Big data in human spinal cord injury: What can be learned to advance clinical practice and trials?

Dr John Kramer¹, Dr Armin Curt², Dr Adam Ferguson³, Dr Catherine Jutzeler⁴

¹University Of British Columbia, Vancouver, Canada, ²University Hospital Balgrist, Zurich, Switzerland, ³University of California, San Francisco, San Francisco, United States, ⁴Swiss Federal Institute of Technology, Basel, Switzerland

For more than a decade, the term “big data” has been used to describe the increasing volume of health information available to inform medical practice. However, for many, the question of how big data has changed the delivery of healthcare remains unanswered. In the field of spinal cord injury, big data is emerging as an important resource to: 1) examine factors that modify recovery from spinal cord injury, 2) improve the accuracy of early prognosis, and 3) perform stratification of patients for clinical trials. The aim of this introductory workshop, designed for clinical trialists, clinicians, researchers, and consumers, is to describe these existing applications, as well challenges and important areas of future research. After a brief introduction of workshop objectives and speakers, Dr. Adam Ferguson (PhD, University of California San Francisco) will outline the state of the art with regards to performing big data visualization and analysis (15 minutes). Dr. Ferguson will draw from his experience building the Open Data Commons for Spinal Cord Injury and the application of topographical data tools to inform the types of questions that can be addressed with big data, and how workshop participants can support big data clinical initiatives. Next, Dr. Armin Curt (MD, EMSCI, University Hospital Balgrist, University of Zurich) will provide a specific example of how big data analytics informed the design of an ongoing, acute spinal cord injury clinical trial (15 minutes). This will specifically discuss applications of machine learning in the European Multi-Center Study about Spinal Cord Injury. Dr. John Kramer (course chair) will then describe an ongoing initiative to maintain data from completed clinical trials for the purposes of secondary, big data analyses (15 minutes). His presentation will discuss the challenges of building a clinical trial repository, with specific reference to his laboratory’s experience merging data from the Sygen trial and Second National Acute Spinal Cord Injury Study. Finally, Dr. Catherine Jutzeler (PhD, Swiss Federal Institute of Technology) will demonstrate the application of big data analytics to examine complex interactions between the acute management of spinal cord injury and long-term neurological outcomes (15 minutes). Each presentation will be followed by a 5-minute question period. At the conclusion of the workshop presentations, 10 minutes will be available for a summary panel discussion and any additional questions from participants. This will be moderated by Drs. Kramer and Dr. Curt. A handout will be made available to participants that summarizes key points of the workshop.

Women's health following spinal cord injury: Impact of injury to autonomic nervous system.

Prof Andrei Krassioukov¹, Prof Stacy Elliott¹, Prof Claes Hultling², Prof Fin Biering-Sørensen³, Dr Elena Andretta⁴, Ms. Nora Sandholt²

¹ICORD / University Of British Columbia , Vancouver, Canada, ²Spinalis, Karolinska Institute, Stockholm, Sweden,

³University of Copenhagen, Denmark Clinic for Spinal Cord Injuries, Copenhagen , Denmark , ⁴Urology Department, Venice, Italy

There is a significant gap in the clinical and research data regarding women's health following spinal cord injury (SCI). This course will start with testimonial from women with SCI on their personal experiences and health issues that they faced following SCI. Through the presentation of multidisciplinary team you will have a unique possibility to see a spectrum of perspectives and opinions and to participate in discussion on crucial aspects of women's with SCI health. This course will specifically address issues of women's with SCI health that impacted by abnormal autonomic nervous system control that resulted from this devastating injury. Specifically we will address topics of changes in menstrual cycle, hormonal profile, bladder, bowel, and fertility issues. We also address issues related to women's health during pregnancy and postpartum period including breastfeeding. Specifically the following topics will be addressed:

Ms. Nora Sandholt. Personal testimony of women with SCI.

Prof. Stacy Elliott. Sexual function, contraception, fertility , pregnancy problems.

Prof. A. Krassioukov. Changes in cardiovascular control in women's with SCI.

Prof. Claes Hultling. Maternal outcomes from Spinalis: Swedish National Board of Health and Welfare.

Prof. Fin Biering-Sørensen. Gynecological Issues and Incontinence among women with Spinal Cord Injury.

Dr. Elena Andretta. Bladder management during pregnancy in SCI: literature and real life.

Questions and discussion

Good Clinical Practice Guidelines in Clinical Research with Spinal Cord Injury Individuals

Dr Jörg Krebs¹, Dr Angela Frotzler¹, Andrea Prusse²

¹Swiss Paraplegic Centre, Nottwil, Switzerland, ²Spinal Cord Injury Center, Balgrist University Hospital, Zürich, Switzerland

Angela Frotzler, PhD MBA (30min) - nothing to disclose

The first part of the workshop will provide a general overview of the benefits and requirements of the ICH GCP E6 (R2) guideline. The emphasis will be on the role and the responsibilities of the sponsor-investigator. The requirements of a research oriented, risk-based quality management system (QMS) and risk-based monitoring will be discussed in the context of feasibility and practicability in the daily clinical routine. The benefits and limitations of standard operation procedures (SOP) or working instructions as tools for quality assurance will be elucidated.

Jörg Krebs, Dr. med. PhD (30 min) - nothing to disclose

The second part of the workshop will aim at providing a deeper insight into the requirements and challenges of data management, data handling and documentation during clinical research, according to the ICH GCP E6 (R2) guideline. The principles and challenges of data management will be discussed on the basis of practical examples. Furthermore, reporting requirements during clinical trials will be discussed.

Andrea Prusse, Study Coordinator (30 min) - nothing to disclose

In the third part, we will focus on practical issues during the implementation of the ICH GCP E6 (R2) guideline in clinical trials. On the basis of an exemplary multicenter, high-risk, interventional clinical trial with spinal cord injury individuals, diverse aspects and challenges in the implementation of GCP will be presented and discussed. A special focus will lay on the feasibility and hurdles of implementing GCP guidelines. Realizable solutions for GCP-requirements will be presented.

Virtual reality rehabilitation interventions to improve motor functions and reduce pain after spinal cord injury

Dr Catherine Mercier^{1,2}, Dr Dolores Soler³, Dr Zina Trost⁴, Dr Michael Villiger⁵

¹Laval University, Quebec City, Canada, ²Center for Interdisciplinary Research in Rehabilitation and Social Integration (CIRRS), Quebec City, Canada, ³Fundació Institut Guttmann, Neurorehabilitation Hospital, Barcelona, Spain, ⁴University of Alabama, Birmingham, USA, ⁵Davos Hospital, Davos, Switzerland

Following SCI, a significant portion of rehabilitation focuses on improving motor function. However, pain also affects the majority of individuals with SCI and can have a tremendous impact on motor recovery and on the quality of life. Virtual reality (VR) interventions have long been known to affect acute pain via distraction mechanisms, but there is growing evidence that these tools can also be used to address more complicated and chronic manifestations of pain. Over the last decade, VR rehabilitation approaches have been increasingly employed both to improve motor functions and reduce pain among individuals with SCI and other related conditions; such VR interventions may represent an opportunity to address several consequences of a SCI in a more integrated manner.

In this symposium, we will explore various approaches that have been recently developed and assessed in individuals with SCI to improve motor function, decrease pain, or both. Catherine Mercier (Laval University) will discuss basic science findings supporting the need to address pain and motor recovery in an integrated manner, and will present results of a study using a VR-based complex gait training to improve locomotion and decrease pain after SCI. Dolores Soler (Institute Guttmann) will focus on the development and application of VR combined with non-invasive brain stimulation techniques targeting lower and upper limbs in patients with SCI, as well as on clinical factors which predict clinical responses in this type of treatment. Dr. Zina Trost (University of Alabama at Birmingham) will present recent findings from an ongoing international research program that draws on the utility of visual illusory feedback therapies to develop an immersive virtual walking intervention for individuals with complete paraplegia and SCI-related neuropathic pain, with concurrent examination of underlying brain mechanisms of action. She will also present novel efforts to utilize virtual embodiment to address loss of sensory function among individuals with incomplete SCI. Finally, Michael Villiger (Davos Hospital) will present an innovative VR training performed at home (i.e. unsupervised) with individuals with an incomplete SCI and stroke, in which virtual representations of the legs and feet are controlled via movement sensors. Furthermore, he will present a new system targeting interactive cardiovascular training.

The symposium will include the presentation of several videos to give a concrete idea of how these approaches are implemented. It will take advantage of the fact that several of the speakers have developed conceptually related VR interventions using different approaches to exchange on our current knowledge about the optimal parameters for the implementation of VR interventions. For example, how important is the level of interactivity? What is the optimal duration and frequency of VR sessions? Should VR be combined with other types of therapy, and if yes, how? What patients are likely to benefit from VR? How should we deal with potential adverse effects, for example, pain provocation?

The symposium will conclude with a 15 minutes roundtable with a question and answer session. The authors have no conflict of interest to declare.

Mechanical Ventilation in Spinal Cord Injury Leads to Increased Morbidity and Mortality: The Worldwide Interdisciplinary Experience in Addressing This Problem

Dr. Raymond Onders¹, Dr. Jesus Benito², Dr. Peter Wijkstra³, Dr. Marc Landscheid⁴

¹University Hospitals Cleveland Medical Center, Cleveland, United States, ²Institute Guttman, Neurorehabilitation Hospital, Badlona, Spain, ³Center for Home Mechanical Ventilation, University Medical Center Groningen, Groningen, Netherlands, ⁴BGU Murnau Emergency Hospital, Murnau, Germany

Three learning objectives:

1. Review acute and chronic management of tracheostomy mechanical ventilation in SCI
2. Discuss how mechanical ventilation and diaphragm pacing impacts SCI rehabilitation
3. Describe the use of early implantation of diaphragm pacing

Participant Level: Material is suitable for any level.

Target Audience: Any healthcare team (physician, respiratory therapy, nursing, physical therapy and consumers) member who may be involved in the care of ventilated patients.

ABSTRACT

Introduction: Dr. Onders General Surgeon, United States (15 minutes)

Spinal Cord Injury (SCI) can lead to catastrophic respiratory failure requiring invasive mechanical ventilation (MV). During the initial hospitalization there is a 60% ventilator associated pneumonia (VAP) rate. MV drastically increases the mortality rate of patients of all ages. According to the National Spinal Cord Injury Statistics, there has been a drastic decline in survival from 2010 to 2018 for a 20 year old SCI on MV from 17.1 years to 11.3 years. MV frequently leads to a delay in rehabilitation which subsequently decreases quality of life.

This workshop intends to review basic respiratory mechanics in SCI that lead to mechanical ventilation, the problems associated with mechanical ventilation and the role of diaphragm pacing in this population. Recent reports demonstrate that DP is associated with a significant decrease in short term mortality of 15% to 3% (Kerwin et al, 2018) and improved median long term survival to 22.2 years (Onders et al, 2018).

Chronic Mechanical Ventilation in Spinal Cord Injury- The Dutch Experience: Dr. Wijkstra Pulmonologist, Netherlands (20 minutes)

Spinal cord injured patients, even those with low thoracic injuries have some degree of respiratory compromise. When levels are in the high cervical region, mechanical ventilation is often needed and becomes chronic in 30% of the population. Despite chronic mechanical ventilation, sputum immobilization is frequently present and pneumonia will develop. Management of chronic mechanical ventilation will be discussed. Optimizing the care of patients on chronic mechanical can decrease the complications. Review of management techniques will be highlighted.

Chronic Respiratory Failure and its effect on Spinal Cord Rehabilitation: Dr. Benito Rehabilitation Specialist, Spain (20 minutes)

It is widely understood SCI patients progress optimally when transitioned from ICU after initial injury to SCI rehabilitation. For patients dependent on tracheostomy mechanical ventilation, rehabilitation efforts can be thwarted. First, there are minimal facilities willing and able to accommodate a ventilated patient. Second, accommodating the actual ventilator and tubing can interfere with activities. Management of respiratory failure while optimizing rehabilitation will be addressed. The transition to diaphragm pacing as a ventilatory mode in a rehabilitation hospital will also be highlighted.

Temporary Diaphragm Pacing During the Acute Injury Phase: Dr. Landscheid Trauma Surgeon, Germany (20 minutes)

Ventilator Induced Diaphragm Dysfunction rapidly occurs in patients post traumatic injury while on MV. New mechanisms to shorten the initial ICU stay can include the use of temporary diaphragm pacing to maintain diaphragm muscle which will be reviewed. Early direct visualization of the diaphragm can also identify non-weanable patients. An acute trauma hospital experience from initial ventilator management and assessment for diaphragm pacing will be discussed.

Fifteen minutes will be left for questions and discussion.

From Concept to Practical Application: Meaningful Consumer Engagement in SCI Research

Ms Emma Peleg¹, Professor Kim Anderson², John Chernesky³, Dr Johnny Bourke⁴, Ms Kristine Hendry¹, Assoc. Professor DJ Brown¹

¹Spinal Research Institute, Kew, Australia, ²North American Spinal Cord Injury Consortium, New York, USA, ³Rick Hansen Institute, Vancouver, Canada, ⁴Burwood Academy of Independent Living, Christchurch, New Zealand

Early and ongoing consumer* input throughout the research process is necessary to improve the number of spinal cord clinical trials with meaningful outcomes that are able to be translated into clinical practice. Local and global momentum is building to engage meaningfully and effectively with consumers in the research process. Placing greater value on the lived experience to improve policy, service delivery and research to achieve more relevant outcomes, is needed to affect this paradigm shift.

Consumer engagement can enhance the integrity of research and has been shown to increase study enrolment rates, aid in securing funding, and improve study design, protocols and choice of relevant outcome measures¹. Furthermore, involving consumers as partners can legitimately value and recognize their knowledge and experience, and has the potential to leave researchers feeling more positive and rewarded^{2, 3}.

Consumers can be engaged at a variety of levels at all points throughout the research cycle, as partners, experts, advisors, advocates or through personal engagement⁴. Opportunities that enable consumers to develop expertise in areas of interest, while matching their skills to a role's requirements, are a necessary component of effective consumer engagement¹.

Objectives

- Recognise the different types of consumer engagement and understand the requirements for engaging consumers as equal partners
- Learn how to take the next steps in engaging those with lived experience in the research process
- Identify tools and programs needed to facilitate and support the connection of consumers with the research community throughout the research process

Material is suitable for participants of all levels with the target audience of those with lived experience of SCI, researchers, allied health, clinicians, scientists and anyone interested in engaging consumers throughout the research process.

Prior learning, experience or qualifications are not essential. Pre-readings are recommended for optimal participation and can be found the SCoRH website [www.scorh.org].

Chair - Dr Kim Anderson-Erisman, President, North American SCI Consortium (NASCI)

Kylie Cochrane, Board Director, International Association for Public Participation (IAP2) Australia, (zoom conference)

- o Overview of consumer engagement and its' value
- o Obstacles and lessons learnt

John Chernesky, Consumer Engagement Lead, Rick Hansen Institute (RHI)
o Guiding principles for successful consumer engagement in SCI research

Dr Johnny Bourke, Disability and PLEx Research Lead, Burwood Academy of Independent Living (BAIL)
o Consumer engagement programs and tools

Development session

o Knowledge exchange with audience, comments and discussion

Sponsoring Organisations

NASCIC, RHI, BAIL, SRI

*Consumer: individuals with lived experience of SCI, their family and friends

1Domeq et al. 2014 <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-89>

2Cancer Australia and Cancer Voices Australia, 2011. National Framework for Consumer Involvement in Cancer Control. Cancer Australia.

https://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf

3NHS Institute (National Health Service Institute for Innovation and Improvement). Using design to innovate. 2011 29 May 2011; Available

from:http://www.institute.nhs.uk/innovation/innovation/using_design_to_innovate.html

4Bourke, J. A., Nunnerley, J. L., Snell, D. L., & Sinnott, K. A. (2019). The Burwood Academy: Incorporating the principles of the Independent Living paradigm into rehabilitation research. *International Journal of Human Rights in Healthcare* (in press)

Screening for cognitive and emotional problems in SCI rehabilitation: what, how and what to do with the results

Prof Marcel Post^{1,2}, Mr. Tijn van Diemen^{1,2,3}, Dr. Jane Duff⁴, Professor Ashley Craig⁵

¹Center of Excellence for Rehabilitation Medicine, Utrecht, Netherlands, ²University Medical Center Groningen, Groningen, Netherlands, ³Sint Maartenskliniek, Nijmegen, Netherlands, ⁴National Spinal Injuries Centre, Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust, Aylesbury, United Kingdom, ⁵John Walsh Centre for Rehabilitation Research, Faculty of Medicine and Health, The University of Sydney, Sydney, Australia

Spinal cord injury (SCI) is one of the greater calamities that can happen to a person. In addition to the severe physical limitations, many people with SCI experience cognitive limitations as a result of concomitant brain injury, or as a result of medication, sleep apnea or other sleep deprivation, etc. Many people with SCI also experience psychological distress, either pre-existent or in reaction to the event, disruption of their life and future plans etc. In response to this situation, it is recommended in rehabilitation guidelines to screen for psychological problems early after admission. The degree to which such recommendations have been implemented is, however, variable, mostly incomplete, and the use of screening results in multidisciplinary teams is suboptimal. In this workshop we will highlight three innovative approaches to screening of cognitive and emotional problems among people with recent SCI.

Outline of the workshop:

Marcel Post: Introduction (10 minutes)

Marcel will introduce the workshop and provide an overview of relevant guidelines.

Tijn van Diemen: Screening for psychological problems and strengths (20 minutes)

Tijn will describe recently implemented psychological screening in the Netherlands and how screening outcomes can be used to guide treatment by the rehabilitation team. He will also discuss how results are communicated to persons with SCI.

Jane Duff: Integrating Psychological Screening within MDT assessment (20 minutes)

Jane will present data from the Psychological Health section of the Stoke Mandeville Needs Assessment Checklist and discuss the Appraisals of Disability Scale (ADAPSS), Perceived Manageability and mood sections of this assessment and how psychologists and non-psychologists can use these within rehabilitation.

Ashley Craig: Screening for cognitive impairment (20 minutes)

Ashley will explore causes and impacts of cognitive impairment following SCI and present valid screens that can be used to detect impairment.

Neurourological management of patients with tetraplegia: alternatives to indwelling catheters and spontaneous voiding

Professor Emmanuel Chartier-Kastler¹, Doctor Marie-Aimée Perrouin-Verbe², Doctor Benjamin Bernuz^{3,4}, Professor Brigitte Perrouin-Verbe⁵

¹Urology Department, Hôpital Pitié-Salpêtrière, Paris, France, ²Urology Department, University Hospital, Nantes, France, ³NeuroRehabilitation Unit, Leon Berard Hospital, Hyères, France, ⁴Neuro-Urology Mediterranean Center, La Conception University Hospital, Marseille, France, ⁵Department of Neurological Physical Medicine and Rehabilitation, University Hospital, Nantes, France

The urological consequences of SCI can be devastating, leading to incontinence and renal failure. The management of patients with tetraplegia is even more challenging, especially those who cannot perform intermittent self catheterization (ISC). Indwelling catheters (either urethral or suprapubic) and spontaneous voiding are often proposed, but present high rates of urologic complications. This workshop will focus on alternatives managements for those with high dependency.

(i) Non-continent cutaneous urinary diversion (Emmanuel Chartier-Kastler, chair, 15 minutes + 5 minutes Introduction)

Non continent cutaneous urinary diversion (NCCUD) is a last resort surgical procedure that can be considered when conservative therapies have failed, especially in patients with intractable incontinence, and when the upper urinary tract is severely compromised. The ileal conduit is most commonly used. It allows continence with correct fitting of the stoma in the majority of patients. A regular follow-up by a multidisciplinary team is needed, NCCUD is accompanied by a high rate of early complications, that sometimes require late reoperations.

(ii) Continent cutaneous urinary diversion (Marie-Aimée Perrouin-Verbe, 15 minutes)

Continent cutaneous urinary diversion (CCUD) may be proposed in patients with tetraplegia who are unable to perform ISC. The key point is the selection of patients and assessment of their ability to reach a fake abdominal stoma to perform ISC. Urodynamics must also be performed to know if a concomitant procedure (augmentation cystoplasty or surgery for continence) is required. The main complication is stenosis (tube or skin), that can often be managed by dilation. CCUD is associated with a high rate of patients able to self-catheterize and a high rate of continence.

(iii) Surgical rehabilitation of the upper limb in tetraplegia to allow self-catheterization (Benjamin Bernuz, 15 minutes)

The ability to perform ISC depends mainly on hand ability and on access to the urethral meatus. When necessary (especially in patients with a C6 level of lesion) hand function can be improved by upper limb reanimation protocols consisting in reconstructive surgery (tendon transfert, tenodeses, arthrodeses) combined with specific rehabilitation procedures. The key-grip strength is the key point to allow ISC, and motivational parameters have to be well assessed before this long therapeutic program. This procedure can be combined with CCUD when necessary.

(iv) Sacral anterior root stimulation (Brindley procedure) (Brigitte Perrouin-Verbe, 15 minutes)

Sacral anterior root stimulation associated with sacral deafferentation is an effective procedure, allowing complete voiding in most patients, a high continence rate and a significant decrease of urologic complications. Best indications are patients with complete SCI and uncontrolled neurogenic detrusor overactivity.

In men, the Brindley procedure imposes the wear of a condom. They must be informed that reflex erection and ejaculation will be lost due to the sacral deafferentation. In women, the social environment must be assessed, as they remain dependent on caregivers for the transfer on toilet or bed.

Interactive Discussion (All speakers & workshop participants, 30 minutes)

Professor Chartier-Kastler (chair) and the panel of speakers will engage discussion with the audience, identifying the different approaches that are proposed, their respective characteristics and potential advantages.

The Proof is in the Prevention – A Comprehensive, Collaborative Approach by ISCOS Committees

Dr Jean Gabriel PREVINAIRE¹, Stephen MULDOON², Professor James MIDDLETON^{3,4}

¹Fondation Hopale, Berck-sur-Mer, France, ²Assistant Director, Livability, London, United Kingdom, ³John Walsh Centre Rehabilitation Research, The University of Sydney, Sydney, Australia, ⁴Clinical Director, State Spinal Cord Injury Service, NSW Agency for Clinical Innovation, , Australia

This workshop is a collaborative initiative between ISCoS Prevention, Education and External Relations Committees and will help to inform future prevention priorities and action plan development. Effective prevention programs are comprehensive in scope and typically theory-driven rather than guided by experience or ‘common sense’ and focused mainly on education, which often seem to characterize prevention efforts. The workshop intends to help health professionals, managers, researchers, peers with SCI and policy leaders involved in SCI care and support move beyond a primarily educational approach to being able to implement multifaceted and community-based injury prevention strategies that include policy development for broad impact.

Presentations will be the following:

(i) Assessment, design and delivery of an effective prevention program (Jean-Gabriel Prévinaire, 20 minutes + 5 minutes Introduction)

Arguably, the Haddon matrix has been the most influential tool in the field of injury prevention, distinguishing between the multiple strategies taking place before, during and after an injury event. However, other tools (e.g., the spectrum of prevention) can be complementary and assist practitioners and policy makers in thinking through, evolving, and strategically developing prevention programs. Dr Prévinaire will provide an evidence-based, practical overview of steps in developing and evaluating a prevention program, with some examples of prevention programs that have proven effective.

(ii) The role of education, media and advocacy in prevention campaigns (Stephen Muldoon, 20 minutes)
Prevention is more than education and goes beyond the individual. Stephen Muldoon will describe current ISCOS educational approaches and resources for strengthening the knowledge, skills and capacity of individuals for management, as well as prevention, of SCI or disease. Within the context of this workshop, he will also discuss the broader role of education within prevention campaigns, not only to increase awareness and knowledge or change attitudes and behaviours through psychoeducation, but through effective community education and “media advocacy”. When communicated effectively to the media, public health solutions emphasising shared responsibility gain the attention and support of legislators and policy makers, acting as a catalyst for policy change.

(iii) ISCOS and World Health Organisation (WHO) collaboration to develop cost-efficient and effective strategies to prevent pressure injuries in people with SCI living in low- and middle-income settings (James Middleton, 20 minutes)

Professor Middleton will expand on previous presentations for planning, design and evaluation of pressure injury prevention and health promotion interventions aligned with WHO-ISCoS Collaborative Work Plan, which: (1) are data based and theory-driven, (2) recognize many contributing factors at multiple levels, (3) emphasise behaviour change, skill development and social support, (4) are appropriately timed, tailored and adapted for population and setting, (5) have sociocultural relevance, (6) delivered with fidelity and fit, (7) build effective collaborative community partnerships, and (h) are properly evaluated.

(iv) Interactive Discussion (All speakers & workshop participants, 25 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 planning, research and evaluation of prevention programs will be explored.

Bone impairment following SCI

Dr Christina Anastasia Rapti¹, Dr Yannis Dionyssiotis², Dr Yorck-Bernhard Kalke³, Ass Prof Ruth Marshal⁴, Prof Brigitte Perrouin-Verbe⁵

¹PRM Department, General Hospital "G.Gennimatas", Athens, Greece, ²1st PRM Department, National Rehabilitation Center, Athens, Greece, ³SCI Centre Ulm, Orthopaedic Department Ulm University, Ulm, Germany, ⁴South Australian Spinal Cord Injury Service, Hampstead Rehabilitation Centre, Adelaide, Australia, ⁵Neurologique Hopital St Jacques, CHU, Nantes, France

During the acute, sub-acute, and chronic phase of SCI bone turnover is affected. Bone mineral density of lower limbs is decreased up to 28-50% below that of age-matched peers at 12–18 months post injury, coexisting secondary etiologies of osteoporosis may be present, and during ageing additional loss of bone occurs. All these compose a complex canvas of bone impairment after spinal cord injury and make the therapeutical approach challenging. The risk of fragility fractures is increased after the 2nd decade post SCI affecting the functionality and quality of life of individuals with SCI. The lack of evidence-based clinical guidelines for the bone impairment diagnosis and management in SCI requires interdisciplinary cooperation and appropriate planning of future research and interventions. This workshop will work towards the development of a position statement.

1. Learning objectives:

- Pathophysiology of bone impairment post SCI
- Diagnosis and management of “sublesional osteoporosis” during acute and sub-acute phase of SCI
- Diagnosis and management of “sublesional osteoporosis” during chronic phase of SCI

2. Participants at an ‘Intermediate’ or ‘Advanced’ level

3. Target audience (physicians, nurses, physios, researchers, consumers, etc.)

4. Pre-reading of recommended articles, which will be discussed during the workshop, is optional

5. Outline of the workshop

- Do we need guidelines on the prevention and management of “sublesional osteoporosis”?

Christina-Anastasia Rapti (15’)

- Is prophylaxis for osteoporosis indicated after acute spinal cord injury?

Yannis Dionyssiotis (15’)

- Management “sublesional osteoporosis” in chronic phase of SCI. The guidelines of the German speaking medical society of paraplegiology (DMGP)

Yorck Kalke (15’)

Discussion (15’)

- Scholiasts:

Brigitte Perrouin-Verbe (10’)

Marshal Ruth (10’)

Discussion (10’)

The 2019 revision of the International Standards for Neurological Classification of Spinal Cord Injury - What's new?

PD Dr.-Ing. Ruediger Rupp¹, Dipl.-Inform. med. Christian Schuld¹, M.D. Steven Kirshblum²

¹Heidelberg University Hospital - Spinal Cord Injury Center, Heidelberg, Germany, ²Kessler Institute for Rehabilitation, West Orange, USA

The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) represents the gold standard for determination of the level and severity of an SCI. Over the years, ISNCSCI has undergone several revisions with its eighth edition released in April 2019. The most recent changes include:

1. A new taxonomy for documentation of non-SCI related impairments, such as peripheral nerve injuries, fractures, burns, pain or age-related muscle weaknesses. Previously, the "5*" was foreseen for cases, where the full muscle strength is not achieved, but the examiner thinks that it would be achieved if the non-SCI condition was not present. However, this approach is limited to the motor examination only and the actual examination score is lost unless explicitly documented in the 'Comments Box.' To overcome this, a general '*'-concept has been introduced where abnormal examination scores can be tagged with a '*' to indicate that non-SCI conditions impacts the examination results. If an examiner tags a score with the '*', details on the reason for this and how this score should be handled during the classification process need to be specified in the 'Comments box'. While '*'-tagged scores above the sensory/motor level will in most cases be handled as normal during classification, '*'-tagged scores at or below the motor/sensory level will typically be handled as not normal. Each classification variable resulting in defined levels or ASIA (American Spinal Injury Association) Impairment Scale (AIS) which is affected by the '*'-tagged scores, should also be designated with a '*'. By this, it is clearly indicated that the classification results are based on clinical interpretation.

2. The Zone of Partial Preservation (ZPP) definition has been refined. In prior ISNCSCI editions, ZPPs were only defined for AIS A injuries, which is not intuitive and restricts the value of ZPPs for effective clinical communication to complete lesions only. Motor ZPPs are now defined and should be documented in all cases including patients with incomplete injuries with absent Voluntary Anal Contraction (VAC). The sensory ZPP on a given side is defined in the absence of sensory function in S4-5 (Light Touch, Pin Prick) on this side as long as Deep Anal Pressure (DAP) is not present.

An analysis of data from the European Multicenter Study about Spinal Cord Injury (EMSCI) found that in one-third of the incomplete patients meaningful ZPPs can be provided with the new definition. A deeper analysis of the EMSCI datasets revealed that the prognosis of the lower extremity motor score after one year is more reliable with the new definition of the ZPP.

This workshop will be an interactive session to get informed about the newest ISNCSCI changes and participants are encouraged to participate in the classification of cases:

- 1) Changes of the 8th ISNCSCI edition – 5 Mins (R. Rupp)
- 2) Documentation of non-SCI related impairments – 25 Mins (R. Rupp)
- 3) New definition of Zones of Partial Preservation – 25 Mins (C. Schuld)
- 4) Interactive classification of difficult cases – 25 Mins. (S. Kirshblum)
- 5) General feedback - 10 Mins.

Results from a randomized clinical trial of 36 sessions of exoskeletal-assisted walking in persons with chronic SCI

Dr. Ann M. Spungen^{1,2}, Dr. Peter Gorman^{3,4}, Dr. Gail F. Forrest^{5,6}, Dr. Jill M. Wecht^{1,2}

¹Department of Rehabilitation and Human Performance, Icahn School of Medicine, New York, United States, ²Spinal Cord Damage Research Center, James J. Peters VA Medical Center, Bronx, United States, ³University of Maryland School of Medicine, Baltimore, United States, ⁴University of Maryland Rehabilitation and Orthopaedic Institute, Baltimore, United States, ⁵Kessler Foundation, West Orange, United States, ⁶Rutgers New Jersey Medical School Rutgers, the State University of New Jersey, Newark, United States

Introduction: Restoration of ambulatory function and the subsequent improvement of health has long been a goal of spinal cord injury (SCI) rehabilitation research. A preliminary pilot study of the use of exoskeletal walking devices performed at the James J. Peters VA Medical Center demonstrated that ten participants with SCI were able to use an exoskeleton to successfully walk for four to six hours per week for three months in a supervised hospital environment. These pilot study participants also demonstrated significant improvement in body composition and improved bowel function. It is unknown if a larger sample of persons with SCI can be taught to walk in these devices with a comparable proficiency and competence, and if they will demonstrate similar medical- and health-related benefits from this intervention. **Design:** A three-center Phase III, randomized controlled clinical trial (RCT) was performed using a crossover design and employing an exoskeletal-assisted walking intervention. The experimental arm was compared to a usual activities arm, as the control, in 50 persons with chronic SCI (> six months post injury) who were wheelchair-users for community mobility. **Primary Aim:** To determine changes in exoskeletal assisted walking (EAW) abilities after 36 sessions; **Secondary Aims:** 1) To improve bowel function as measured by established survey instruments; 2) To reduce total body fat mass and fat percent as measured by dual-energy X-ray absorptiometry (DXA). **Exploratory Aims:** 1) To improve autonomic/cardiovascular function (vagal tone) measured by the high frequency component of 24-hour heart rate monitoring; 2) In persons with injury level T6 and above, to improve orthostatic tolerance measured by the sit-up-test; 3) To improve HDL-c, Homeostatic Model of Assessment – Insulin Resistance (HOMA-IR), serum total testosterone and estradiol levels measured by serum and plasma assay kits; 4) To improve quality of life (QOL) measured by item banks from the SCI-QOL and Patient Reported Outcomes Measurement Information System (PROMIS). **Results:** The enrollment goals have been met for this study, the trial has been completed, and data analysis is ongoing. Data will be presented on the enrollment numbers (including number of screen failures and reasons) and the results of the outcome measures listed. **Conclusions:** The relevance of exoskeletons for implementation in clinical practice including a cost/benefit discussion in the form of an open exchange with the audience will be provided.

Chairperson: Ann M. Spungen, EdD (15 min) Overview of the study design, methods, and consort data (enrolment, screen failures and reasons)

Speaker 1: Peter Gorman, MD (15 min) GI and endocrine results

Speaker 2: Gail Forrest, PhD (15 min) Kinematic/biomechanical results

Speaker 3: Jill M. Wecht, EdD (15 min) Autonomic nervous system results

Chairperson: Ann M. Spungen, EdD (10 min) Summary, discussion of clinical implications and cost/benefit of this technology

Speaker time: 70 min; **Q&A:** 20 min; **Total Workshop time:** 90 min

This study was funded by the Department of Defense, Congressional Directed Medical Research Program, Spinal Cord Injury Research Program Clinical Trials (Grant #11501833/SC130234; Dates: 10/2014 to 09/2019). None of the authors have any conflicts of interest to report.

New Horizons in the Diagnosis, Clinical Care Pathway and Research of the SCI Spasticity Syndrome: a focus on disabling symptom management to improve residual neuromuscular function and quality of life

Dr Julian Taylor¹

¹*Sescam & University Of Oxford, Toledo, Spain*

1. Title: New Horizons in the Diagnosis, Clinical Care Pathway and Research of the SCI Spasticity Syndrome: a focus on disabling symptom management to improve residual neuromuscular function and quality of life.

2. Speakers:

Dr. Fin Biering-Sørensen MD, DMSc. University of Copenhagen, Denmark.

Dr. Peter New MBBS, M Clin Epi, PhD, FAFRM (RACP), Caulfield Hospital and Monash University, Australia.

Dr. Julian Taylor Ph.D, Hospital Nacional de Paraplégicos and University of Oxford (Chairperson).

3. Learning Objectives:

- Understand the clinical presentation and impact of the spinal cord injury spasticity syndrome, including standard diagnosis using the International Spinal Cord Injury Musculoskeletal Basic Data Set and Modified Ashworth Scale, including the impact of symptoms.
- Comprehend the clinical care pathway for optimizing the management of spasticity in people with spinal cord damage according to the international Ability Network.
- Appreciate the importance of measuring cutaneous hyperreflexia in relation to characterising the SCI spasticity syndrome, its impact on lower limb neuromuscular function and modulation using physical techniques (TENS and vibration), activity-based rehabilitation (ergometer) and non-invasive spinal neuromodulation.

4. Material: appropriate for participants at any level.

5. Target audience: Physicians, nurses, physios, occupational therapists, researchers.

6. No prior learning, experience or qualifications are required for the workshop.

7. Outline of the workshop – please list what each speaker will present and the time allocated to each speaker.

Each speaker will speak for 25 minutes with 5 minutes for questions. Open and semi-structured questions will be included to gauge awareness of the topic and to consolidate new information.

Dr. Fin Biering-Sørensen: An update on the assessment of spasticity after spinal cord injury and management of high impact symptoms. The first speaker will provide the latest update of the ISCOS musculoskeletal basic data set, diagnostic tools, impact of SCI spasticity symptoms and future treatment perspectives.

Dr. Peter New: Optimizing the management of spasticity in people with spinal cord damage: a clinical care pathway for treatment decision-making from the Ability Network, an international initiative. The second speaker will give an overview of spasticity management in people with spinal cord damage can be complex

and challenging, and will cover evidence-based spasticity management within the context of a clinical care pathway developed by the Ability Network.

Dr. Julian Taylor: Spinal hyperreflexia as a research tool to assess the impact of SCI spasticity syndrome and as a benchmark for therapeutic effects of activity-based neurorehabilitation and neuromodulation. Hyperreflexia will be described as a translational metric to characterize spasticity in people during the subacute SCI rehabilitation phase, and how cutaneous hyperreflexia can be used to benchmark the modulatory effect of physical intervention, activity-based rehabilitation and non-invasive neuromodulation.

8. Equipment: No demonstration of assistive technology or equipment will be made.

9. Conflict of Interest: The speakers of this workshop will provide disclosure information about potential conflicts of interest in the first slide of the presentation and will avoid any commercialization, promotion or advertising of products or materials.

Tele-Health beyond telemedicine: is it the future?

Miss Nishu Tyagi¹, Dr Marcalee Alexander², Dr Shakti Amar Goel¹, Ms Ingebjørg Irgens³, Dr Francois Theron⁴

¹Indian Spinal Injuries Centre, Delhi, India, ²University of Alabama and Telehealth Sexuality Clinic, Birmingham and Boston, USA, ³Sunnaas Rehabilitation Hospital, Nesodden, Norway, ⁴Netcare Montana Private Hospital, Gauteng, South Africa

Learning Objectives:

- i. Basic guidelines to set up the telehealth support unit.
- ii. Telehealth support is more than just a telephonic/video consultation.
- iii. Examples of telehealth solutions: success stories
- iv. Low cost innovations & its impact on telehealth service delivery in LMIC communities
- v. How digital literacy is important and required for the patients/caregivers.
- vi. Telehealth as an outreach service delivery model in developing nations.
- vii. Other tele-services: Tele research, Tele-Prevention, Tele Rehab, Tele-consultation, Tele-education.
- viii. Practical application of ISIC telehealth services so far in follow-up care and prevention.

S. No Topic Duration Faculty

- 1 Introduction and Activity Questionnaire Distribution Audience
- 2 Telehealth and sexuality 10 min Dr. Marcalee Alexander Speaker
- 3 Case study: Educational Program 10 min Dr Ingebjorg Irgens Speaker
- 4 Hospital-based care at home after SCI 10 min Dr Ingebjørg Irgens Speaker
- 5 Value of telehealth and tele-rehab across business and service models. (Practical Solutions to Existing Issues)

ISIC – Telehealth centre of learning

10 min

Ms Nishu Tyagi/

Dr Shakti Goel Speaker

6 Telehealth : Scope for collaboration (ISCoS) 10 min Dr. Marcalee Alexander Speaker

7 Activity Based learning: Telehealth/Tele-rehab

15 min Ms Nishu Tyagi,

Dr Ingebjørg Irgens Audience : Activity Based Learning

8 Case studies/ success stories 10 min Dr Marcalee Alexander Speaker

9 Panel Discussion: Telehealth in current Consumer practice. 15 min Moderator: Ms. Nishu Tyagi

Experts: Dr Francois Theron, Dr Marcalee Alexander, Ingebjørg Irgens Audience

To walk or not to walk: the current state of the use of exoskeletons in patients with spinal cord injury

Prof. Fin Biering-Sørensen^{2,3}, Dr Marco Molinari⁴, Drs Rosanne van Dijsseldonk¹, Dr Edwin van Asseldonk⁵, Dr Ilse van Nes¹, Dr Noel Keijsers¹, Dr Marije Vos¹

¹Sint Maartenskliniek Nijmegen, The Netherlands, Nijmegen, Netherlands, ²University of Copenhagen, Copenhagen, Denmark, ³Clinic for Spinal Cord Injuries, NeuroScience Centre, Havnevej, Hornbæk, Denmark, ⁴Neuro-Robot Rehabilitation Lab; IRCCS Fondazione, Santa Lucia, Rome, Italy, ⁵University of Twente, Enschede, the Netherlands

One of the major consequences of a spinal cord injury (SCI) is the loss of mobility. People with a complete SCI have lost the opportunity to walk and patients with an incomplete SCI often need assistive devices. Due to the current technological innovations, possibilities for improvement of walking capacity have increased. A powered exoskeleton is such an intervention. By the use of an exoskeleton people can overcome obstacles like stairs and there may be a positive psychological effect of standing upright. The use of an exoskeleton may also have a positive effect on health issues like spasticity, bladder and bowel function and back pain. Currently, powered exoskeletons are used for the training of walking function in patients with incomplete SCI and for compensation of walking in patients with complete SCI. Previous studies have shown that the training is feasible and safe (Miller et al, 2016; Baunsgaard et al, 2017; van Dijsseldonk et al, 2017). During this workshop we will present the experiences and results of these training programs in both complete and incomplete SCI from several European sites. Furthermore, some advices for use in daily clinical practice will be given.

So far, various improvements are needed for exoskeleton use at home during daily routines. One of the most mentioned improvements, both by users and clinicians, is the ability to use an exoskeleton without crutches. In the last part of this workshop we will therefore focus on the balance control of powered exoskeletons and what is necessary to make a next step in the future of wearable exoskeletons.

Presentations:

Prof Biering-Sorensen: Gait training after spinal cord injury: safety, feasibility and gait function after training with the exoskeletons from Ekso Bionics- results of a multicenter study

Dr Molinari: Advanced technology in the clinic for everyday neurological rehabilitation, use of exoskeletons, translation to clinical use

Drs van Dijsseldonk/ Dr van Nes: Feasibility and functional use of exoskeleton in complete SCI- results of use at home

Dr van Asseldonk: Towards improved support of balance in exoskeletons technical innovations end development

Microbiome and Spinal Cord Injury: Past, present and future!

Dr Matthias Walter¹, Prof John Steeves¹, Dr. Bilge Yilmaz², Dr. Kristina Kigerl³

¹University of British Columbia, Vancouver, Canada, ²Department of Physical Medicine and Rehabilitation, Gulhane School of Medicine, University of Health Sciences, Ankara, Turkey, ³Department of Neuroscience, The Ohio State University Wexner Medical Center, Columbus, USA

Synopsis:

Alterations in microbial composition (taxa) of the gut, as well as metabolomic changes are associated with many seemingly diverse disorders, including: cancer immunotherapies, asthma, cardiovascular disease, and central nervous system (CNS) disorders, such as autism. However, it is not known which comes first - a change in the microbiota or the onset of the disease or disorder. If microbiotic species can be collected soon after spinal cord injury (SCI), it would reflect the microbiotic status prior to the sudden onset of SCI. Subsequent tracking of the microbiome might then allow medically meaningful correlations to be developed leading to potential development of beneficial interventions.

Particular microbiota species, as well as their metabolites alter responses of the immune system, including functions of B cells, helper T cells and regulatory T cells and are suggested to impact relapsing and remitting forms of experimental multiple sclerosis. Alterations of the gastrointestinal microbiota has been linked to increased rates of urinary tract infections and renal stone formation.

There is a need to longitudinally track changes in human urinary tract and gastrointestinal microbiota after SCI. Inflammation and persistent immune reactions are a hallmark after CNS trauma (e.g. SCI, traumatic brain injury and stroke). We know that people with late onset CNS trauma or those individuals who have lived long-term with a traumatic CNS disorder suffer more infections and health complications, as well as a shorter lifespan.

Considering the profound consequences for individuals following SCI and the emerging association between microbiome and humans' health, addressing the following topics are of great interest for any profession involved in the management of individuals with SCI.

This workshop will provide a fundamental overview of the microbiome and its relationship with the immune system. Furthermore, attendees will receive a comprehensive summary of the current evidence from animal and human trials (including our ongoing clinical trial assessing the changes in human urinary tract and gastrointestinal microbiota after SCI, followed by an interactive discussion with the audience.

Overview of workshop topics (total 90 min):

Prof. John Steeves (Introduction to microbiome) – 20 min

1. What is the microbiome (including terminology such as microbiota & metabolomics) and what can we actually investigate (skin, gut, urine, etc.)?
2. Microbiome and the immune system
3. Why is this relevant to humans – Impact and implications, e.g. diabetes, allergies, and neurological diseases ?
4. Microbiome – Limitations and influences

Dr. Kristina Kigerl

5. Microbiome and SCI – Evidence from preclinical animal models, including the value of germ-free mice – 20 min

Prof. Bilge Yilmaz

6. Microbiome and SCI – Evidence from previous human studies – 15 min

Dr. Matthias Walter

7. Presentation of our ongoing multicenter trial including preliminary results – 15 min

All presenters

8. Audience Discussion: Q's and A's – 20 min

Conclusion:

Up-to-date knowledge transfer to everyone who is involved with taking care of individuals with SCI. After attending this workshop, the participant will be able to understand the foundation of microbiome and its relevance to human health. It will provide clinicians, students, healthcare providers and scientist with state-of-the-art information relevant to clinical practice and (future) research in this population.