



**MINUTES ANNUAL GENRAL MEETING**

**6 November 2019 - Nice, France**

<b>16.05</b>	Called to order by Dr H Chhabra
<b>1</b>	<p><b>Report of President – Dr H Chhabra (HC):</b></p> <p>During the last year there has been increased transparency; responding to questions and issues as soon as possible; trying to bring in inclusivity and recognition of the discipline-specific/topic specific working groups; strengthen accountability (Bye-Laws Committee) all Committees asked to set up Action Plans; continuity – will have succession plan for each post and need to add a plan for Secretary as we have for other posts. Zoom meetings have been introduced. Will have 4 meetings per year of Board – 1 in person. Executive meets x 2 during year in person and an additional 2 (minimum) Zoom meetings. Constitution and Bye-Laws Committee will continue to work on revisions and work with the changes per the Strategic Plan.</p> <p><b>Strategic Plan:</b> the way forward and to hear the voices of the members. Draft plan as a template has been circulated to the Strategic Management Committee. Milestones: Will have further online discussions to March of 2020 then circulate draft plan to members, get suggestions, incorporate and circulate again then have a final plan in place. Hope to meet again in Japan to finalize the plan and put it into action. HC went over the slides on the Strategic Plan in detail. Need a financial analysis to take into account past and future performance. Roles of all members of the Strategic Management Committee have been defined.</p> <p><b>A Survey of Affiliated Societies was Conducted:</b></p> <p>There were responses from 15 Affiliated Societies - DGMP got responses to us late but we received and analyzed their data.</p> <p>Will need to have a financial plan to execute the Objectives of the ISCoS Strategic Plan. Will need to seek funding to support additional activities that are outlined in the newly developed Strategic Plan – this is above and beyond what ISCoS already supports. Will prioritize financial issues based on “what do you really need immediately”, “what would you need in the near future” and “what would you like in an ideal situation”. Review of initiatives every 2-5 years.</p>

	<p>Strategic Management Committee will likely need to meet for a full day prior to each Annual Scientific Meeting.</p> <p><b>Discussion with ASIA:</b> We could not work out arrangements to have Spinal Cord be the official journal of ASIA but we continue to explore ways to increase the reach of the journal. A joint meeting with ASIA was explored but due to various issues, we cannot have a joint meeting in 2021 and will explore a meeting in a future year. Also will explore joint meetings with other affiliated societies. The Chair of the Prevention Committee has attended the recent ASIA meeting to liaise with their Prevention Committee.</p> <p>We have a signed collaboration with Cochrane Rehabilitation.</p> <p>Agreement signed with ISPRM to join forces and organize a joint scientific session at our meetings each year pending approval by Scientific Programme Committee, linkage of websites and sharing dissemination efforts.</p> <p>Collaboration with Child Health International (MOU). With this we hope to have a Special Interest Group (SIG) on Pediatric Spinal Injury Management and increase discussions on this topic in the future.</p> <p>Discussions are ongoing related to journal changes and what is happening with Editorial Assistance.</p>
	<p><b>Report of Secretary – Dr S Charlifue (SC):</b></p> <p>The Minutes from the meeting in Sydney, Australia in 2018 were ratified.</p> <p><b>Deaths:</b> Dr Paul Dollfus – Founding member, Past President and Society Medal holder Dr. Dietrich Eckhard Leder (Germany), also a member of DGMP</p> <p><i>Moment of silence</i></p> <p>The 2019 Society Medal was awarded to Mr B Gardner, UK</p> <p><b>President-Elect:</b> Following electronic voting by the membership prior to the AGM, the result was Ratified by those present and A/Prof Ruth Marshal, Australia was duly elected President Elect.</p> <p><b>Treasurer:</b> Following electronic voting by the membership prior to the AGM, the result was Ratified by those present and Dr E M Hagen, UK was duly elected Treasurer for a 3 year term.</p> <p><b>Chair, External Relations Committee:</b> Prof J Middleton, Australia was re-appointed for a second 3-year term.</p> <p><b>Constitution and Bye-Laws Revisions:</b></p> <ol style="list-style-type: none"> <li>a. Ad hoc committee formed to revise existing documentation.</li> <li>b. Review by ISCoS Executive and Board with further suggestions.</li> </ol>

- c. Revisions incorporated as appropriate.
- d. Further review by Executive, Board and full membership.
- e. Comments incorporated as appropriate.
- f. Final Executive review – no further revisions deemed necessary.
- g. Sent out to ISCoS membership for voting.
- h. Cannot request ratification at Nice AGM as we did not get the required 40% of members voting on the changes. We will be making additional minor changes and the Constitution and Bye-Laws will go out again for a vote and then ratification.

**Membership Information:**

- a. 779 currently paid-up members.
- b. Implementing new system to track membership and subscriptions.
- c. To consider establishing a Membership Committee.

**Upgrades to Website:** including security and privacy, in accordance with European GDPR laws.

- a. Will include an area for Affiliated Societies and Allied Discipline Groups.
- b. New social media activities will be available after Nice meeting.
- c. BCD will work on this with the Chair of the Communications Committee.

A member asked for the positive votes from the electronic voting and was informed there was no legal requirement for the percentage of members that voted in order to appoint someone to a position.

**Report of Treasurer – Prof J J Wyndele (JJW):**

Prior to the Annual General Meeting the current Treasurer, Dr MA Jamous had resigned and Prof J J Wyndaele was appointed Interim Treasurer.

Income comes from membership, profit from Annual Scientific Meeting and from the sale of the journals – we get approximately 60%, Nature gets 40%. We have essentially stable income. Reviewed expenditures. Balance sheets reviewed (assets, expenses, investments and overall total balances). JJW term as Interim Treasurer and Executive Officer are now at an end. HC thanked him for all his work over the years.

ISCoS is registered as a Company in the UK. Two members of ISCoS were considered the Directors of the Company. To consider having the Board of Directors of the “Company” be the Executive as well as the Executive Administrator. We need to explore the costs of changing this so probably need to take some legal advice. A member said we should let the new Treasurer explore this issue as well as possible advantages of ISCoS becoming a Charity. Another member suggested we look into having the Society managed from somewhere other than the UK. New Treasurer can take this on to see how this can be organized in the future. HC said the Executive can explore this and will evaluate which is the best way to register the Company taking into consideration the need to look into the aims and outcomes of what we do. Discussion ensued but in interest of time we will delegate this responsibility to the Executive. A member asked if a vote was needed to empower the Executive to move this process forward and come back to the membership

well before the next AGM but another member felt this was not needed and that the Executive has this authority and the membership doesn't need to vote. The newly elected Treasurer automatically would become a signatory and this transfer should not require any legal input. Another member suggested an international lawyer to advise on how to set up ISCoS. HC said this could be part of the process.

**COMMITTEE REPORTS:**

**Communication Committee - Dr T Bryce (TB):**

- All committee members are in their 2nd year of service.
- There are open positions on the committee.
- Ad-hoc volunteer authors have contributed articles to regular features of the Newsletter.

**Newsletter (NL):**

NLs sent to the membership October 2018, November 2018, January 2019, March 2019, April 2019, May 2019, June 2019 and October 2019.

The statistics of the June NL showed that it was sent to 1216 addresses. The open rate was 42% and the click rate was 11.4%; both above the industry average. In that issue, the most opened link clicked was the Presidential message followed closely by the ASIA/ISNCSCI revision update.

In addition to the recurring feature of 'Spotlight' which focused on different current member of ISCoS, another feature was added this year entitled Notable Figures for the History of SCI Care which has been guest edited by ad-hoc volunteer authors.

**Website:**

The Chair continues to help the ISCoS Executive Administer upload resources to the website.

**Social Media:**

A system has been approved by the Treasurer to be implemented whereby BCD will develop and send out approved content via social media channels. The content to be posted will be appropriate and relevant to ISCoS and the Chairs of all the Committees (eventually including the SIGs) and approved by the Chair of the Communications Committee initially before being posted. This has not started as of 10/1/19. Of note funds were requested to support an external person to coordinate the social media outreach but this was not approved.

TB requested help from the membership to help provide input that can be communicated and shared with all.

**Education Committee - Mr S Muldoon (SM):**

**eLEARN:**

**53,300** registered users. From Oct 2016 – Oct 2019 - 82,493 unique visitors; 229,998 visitors (including repeat)

**New Content:**

**Consumer Module:** Being developed to guide SCI consumers with information related to the injury. 3 sub modules completed and uploaded: Outcomes in SCI; Bowel Care; Skin care & Pressure Injury Management.

**Paediatric Sub Module:** (*sub Module within overview for the whole team module*).

This new sub-module is to expand the paediatric related material presently available on [www.elearnsoci.org](http://www.elearnsoci.org), Expected date of completion Dec 2019. Project costs supported through The Spine Foundation, Australia.

**Translations:**

**German:** Nursing Module completed and “live.” Partners DMGP, the German Society of Paraplegia the Manfred Sauer Foundation.

**French:** Modules “Overview for the whole team” and “Physiotherapy” complete and to be officially launched during the ISCoS conference in Nice. Partners AFIGAP and Humanity and Inclusion (HI).

**Arabic Translation:** Continuing.

**Mongolian** Modules “Overview for the whole team” and “Physiotherapy” complete. Content under reviewed and will become “live” this year

**2nd Edition [www.elearnsoci.org](http://www.elearnsoci.org)**

Currently developing a project document and to identify possible funding sources to support associated costs. The project will support upgrading of content, website and interface development and enable the resource to be more accessible through mobile devices. Envisaged to commence in early 2020.

**Workshops/Conferences 2019/2020:**

Curacao/Caribbean, Mongolia, Morocco, Malaysia, Argentina, China, Nigeria, NORDIC Advanced SCI Rehab Course (NASCIR) 2 startup days, 2 closing days Gothenburg Massive Open Online Course (MOOC) for Nurses.

**Partnership – Collaboration – Representation:**

ISCoS EDC has continued to work collaboratively with other standing committees, special interest groups, affiliated societies, networks and related groups including International Network of SCI Nurses. This approach is helping to increase the quality and coverage of educational initiatives and programmes in different parts of the world.

**ISCoS – ASIA Education Committee:** Dr Ron Reeves continues to represent ASIA Education Committee on the ISCoS EDC.

Dr EM Hagan has replaced Dr T Bryce as ISCoS EDC representative on the ASIA Education Committee. Both organisations continue to collaborate particularly in relation to educational programmes in Latin America in collaboration with SLAP.

**Mayo Clinic Abroad:** Through Dr R Reeves the EDC collaborated with Mayo Clinic Abroad (MCA) in support of the SCI workshop in Mongolia. Support included the provision of resource persons and trainers. In 2020 MAC have awarded funding for 2 MCA Nurses. With ICU/Acute care/Emergency Room experience the nurses will help deliver SCI Acute Care Nursing Education in support of the ongoing efforts in Africa and Mongolia.

**ASCoN Training Centres:** The EDC worked closely with ASCoN Training Centres in South Korea and Malaysia in relation to the delivery of the workshop in Mongolia and the ASCoN Conference and Training of Trainers Programme.

**Humanity and Inclusion and Livability:** EDC in collaboration with HI and Livability have developed a field manual and resource for PTs/OTs planning to deploy and/or working in conflict and disaster scenarios. An SCI Chapter Working Group was established with representation from the ISCoS EDC and ERC/Disaster Committee, including, F Stephenson, E Weerts, M Baumberger and S Muldoon. The final draft chapter has been completed, and the review process is ongoing.

EDC members S M and E Weerts, through Livability and HI, are working with the Ministry of Health in Myanmar to establish a National SCI Service Delivery and Human Resource Development Programme. Going forward this is a future project that will benefit from the inputs of the EDC, ERC and Prevention Committee.

**Representation:** The Chair and EDC members continue to promote the work of ISCoS and Educational activities during meetings and conferences in different parts of the world.

**External Relations Committee - Prof J Middleton (JM):**

- Responsible for engaging with key organisations to accomplish the Society's mission to advise, promote and support access to high quality care, education, prevention, research and innovation for persons with spinal cord injury.
- Chair and 10 core members - providing global coverage of Affiliated Societies, Networks and WHO regions, as well as Liaison and Advisory members.
- Three subcommittees, comprising:
  - WHO-Liaison / External Societies
  - Disaster
  - Affiliated Societies. Reviewing terminology and criteria regarding Affiliated Societies.

**Membership:**

- Prof James Middleton (Chair, WHO-Liaison / External Societies)
- Prof Shinsuke Katoh (Chair, Disaster Subcommittee)
- Prof Anba Soopramanien (Chair, Affiliated Societies Subcommittee)
- A/Prof Colleen O'Connell (ISCoS-Liaison to ISPRM)
- Rainer Abel (Europe; ISCoS representative to GRA)
- Prof Apichana Kovindha (resign) (South East Asia, ASCoN) - vacant
- Prof Federico Montero (Latin America and Caribbean)
- Dr Ali Otom (North Africa / Eastern Mediterranean)
- Prof Jianjun Li (Western Pacific)
- Dr Raj Singhal (South Pacific)
- Dr Francois Theron (Sub-Saharan Africa, AFSCIN)
- Mohit Arora (Early Career Member, Secretary)
- Eric Weerts (Humanitarian Inclusion-Liaison)
- A/Prof Julia Patrick Engkasan (ISPRM-Liaison to ISCoS)
- Advisory: Prof Jerome Bickenbach

**WHO-Liaison & Related Activities:**

- Non-State Actor in official relations with WHO.
- WHO-ISCoS Collaborative Workplan (2017-2019) completed with *achievements* including:

- Provision of advocacy / technical support by ISCoS to governments (Myanmar, Mongolia).
- Participation in WHO *Rehab2030 initiative*, with input into *Guide for Action, Package of Rehabilitation Interventions (SCI Technical Working Group)*, and *Workforce Competency Framework*.
- Expert advice for *Minimum Technical Standards and Recommendations for SCI Specialist EMTs* guideline.
- Founding member of Global Rehab Alliance.

**WHO/ISCoS Work Plan (2020-2022):**

- *New work plan (2020-2022)* recently developed, with areas of collaborative work with WHO to include providing technical input towards:
  1. WHO's *Package of Rehabilitation Interventions*, in areas relating to spinal cord injury;
  2. WHO's *Rehabilitation Competency Framework*, pertaining to workforce development in SCI; and
  3. WHO's *Rehabilitation in Health Systems: Guide for Action*, regarding SCI-specific approach for health systems assessment. A major ERC project has been initiated to develop a *SCI Service Module*, including practical tools.

**WHO Package of SCI Rehab Interventions:**

- A Technical Working Group comprising Alexandra Rauch (WHO), Michael Baumberger, James Middleton & Mohit Arora.
  - Defined a list of EB interventions from clinical practice guidelines as basis for Consensus process.
- Development Group for SCI will be assigned to:
  - Agree on inclusion of evidence-based rehabilitation interventions in the PRI for Spinal Cord Injury.
  - Identify target areas not addressed in the list.
  - Agree on the appropriate service delivery platform and service level (essential or optional interventions) for each of the selected interventions.

**External Societies:**

- ISCoS & ISPRM collaboration on *Learning Health Systems - International SCI Survey* (LHS-InSCI project).
- ISCoS & Humanity Inclusion – Standards & Resources for Disasters
  - Working Group for *SCI in Emergencies Guidance for Emergency Medical and Specialist Care Teams* (WHO collaborative project).
- Renewed MoU with ISPRM
  - Discussions held with in Kobe in June 2019 with Walter Frontera (President), Carlote Kiekens (Chair, WHO-Liaison) and Julia Patrick Engkasan (ISPRM-Liaison to ISCoS).
  - Will focus on LHS-InSCI project, capacity-building, disaster response, education, development of tools & resources.

**International SCI (InSCI) Survey:**

- InSCI Community survey is a joint initiative between ISCoS and ISPRM, in partnership with Swiss Paraplegic Research (Study Centre).

- 22 countries involved in the study, with 12,591 participants with SCI recruited. Data analysis has commenced.
- Presentations of preliminary results given at:
  - ISPRM Congress, Kobe, Japan (9-13 June 2019)
  - ISCoS Conference, Nice, France (5-7 Nov 2019).

#### **InSCI Survey Plan - Activities / Timetable:**

- Publication of first six *reference papers* (cohort profile, work participation, environmental factors, and so on) in Archives PM&R in early 2020.
- Further *international comparative* and *national* papers will follow.
- Implementation activities based on the findings of InSCI survey are planned to include:
  - improved practice / interventions / services.
  - advocacy with preparation of *Summaries, Policy Briefs and Stakeholder dialogues*.
- A 5-year InSCI survey (2022 / 2023) is also planned.

#### **New MoUs:**

##### *Cochrane Rehabilitation*

- A new MoU between Cochrane Rehabilitation and ISCoS was executed in June 2019. It is aiming to develop and implement joint activities to support and strengthen use of health evidence.

##### *Child-Help International*

- A new MoU is under development with CHI to work together to improve the care and quality of life of children and adults with Spina Bifida and Hydrocephalus, with a particular focus on under-privileged areas of world and in ‘Global South’.

#### **Disaster Sub-Committee:**

- A *SCI in Emergencies* Working Group is being set up to produce an Online Toolkit and Operational Handbook (Blue Book) - *Guidance for Emergency Medical and Specialist Care Teams* in 2020.
- Future plans include:
  - Designing and undertaking a survey for global mapping of *Disaster preparedness and response capacity* for SCI services, collaboration with HI (in 2020).

Update eLearn module (in 2020).

#### **Affiliated Societies Sub-Committee:**

- Prof A Soopramanien appointed as Chair of this new Subcommittee in March 2019. A working group has been meeting by teleconference, comprising Anba, Rainer Abel, Francois Theron, Mohit Arora and James Middleton to progress planning for ISCoS in Nice.
- Affiliated Societies Subcommittee formal launch in Nice.
- Strategic survey of Affiliated Societies and Networks performed in October 2019.
- High priority actions are to develop a communication strategy and platform/s, such as Chat Room on website and/or Social media (e.g., WhatsApp, Facebook group), to raise issues, share resources and work together.

## **Prevention Committee - Dr J G Previnaire (JP):**

### **Members:**

Dr Yu-Ying Chen, Dr R Cripps, Dr Y Dionyssiotis, Dr R Dixon, Prof B Erhan, Mrs Kamrunnaher Koly , Dr P New, Dr CA Rapidi, Guru Nagarajan S, Mr E Weerts.

### **Redefinition of Goals:**

- ✓ Foster collaboration with various organizations
- ✓ ISCoS Affiliated Societies and Networks around the world, WHO.
- ✓ Raise awareness of prevention
  - Within the ISCoS Society
  - Promote the SCI day (5th September each year)
- ✓ Focus on specific causes of injuries
  - Traumatic (RTA, falls, diving, violence in conflict areas...)
  - Non-traumatic (spina bifida, SC dysfunction from tumour or tuberculosis...)
- ✓ Demonstrate the effectiveness of prevention programs
- ✓ Update the global maps for traumatic and non-traumatic SCI epidemiology
- ✓ Further develop and promote the ISCoS Database Project (IDAP)
- ✓ Liaise with the ISCoS host countries for prevention actions

### **Summary of Actions in 2019 :**

- ✓ SCI Day Slogan: 'Living Life to the Fullest'
  - Celebrated in more than 30 countries worldwide
  - Supported by WHO through social media
- ✓ IDAP Project
  - 13 active centers (addition of 2 new centers in Jordan and India)
  - 2172 enrollments so far (from 1566 in 2018)
- ✓ Contact with ASIA Prevention Committee
  - Possibility of joint actions in the future (Chair: Kolakowsky-Hayner)
- ✓ Collaborative Prevention Workshop in Nice
  - Joint workshop with the Education Committee (S Muldoon) and the External Relation Committee (J Middleton)

## **Scientific Committee - Dr G Scivoletto (GS):**

- The 57th Annual Scientific Meeting of ISCoS in Sidney, Australia was held on 13-15 September, 2018 and had over 800 attendees from 46 countries all over the world.
- The meeting was a success; therefore we maintained the same program with 6 plenary lectures (2 per day) and extended poster/exhibit/networking breaks (1 hour in the morning and 1 in the afternoon of each day).
- Rapid fire presentations were well-received and due to the number of abstracts that we received and to the need to help people to deal with bureaucratic requirements (some would not have the authorization to take part to the meeting unless they have an oral presentation), we decided to maintain this format

**Selection of Annual Meeting Sites:**

- Last year in Sydney we decided a plan for our next venues, taking into account the need to have an equal distribution of meetings in Europe, America and less developed countries.
- The 2021 meeting that was scheduled in Canada as a joint meeting with ASIA will be an ISCoS only meeting. ASIA let us know that they cannot meet this date.
- At the present time we will still meet in Vancouver, however, we are looking at another possible country in the Americas that could be available, not too expensive and safe.
- This issue will be further discussed with the PCO and the Executive.

**New Members of the Scientific Committee:**

- We received several requests from ISCoS members to be part of the Scientific Committee.
- There are several members on the committee who are at the end of their term or that contributed less to the activities of the Committee, thus we will probably have space for new members.
- This will be discussed further by the Scientific Committee

**Research Activity of the Society:**

- We have been approached by ASIA Research Committee as they found that a number of potential ISCoS initiatives are also priorities for the Research Committee of ASIA and they wonder if the two organizations should leverage resources, where possible.
- We believe that this could represent a good possibility for both societies and deserves further discussion.
- This will be discussed during the meeting in Nice and a plan for a possible liaison with ASIA will be submitted to the Executive.

**JOURNALS:****Spinal Cord – A/Prof L Harvey (LH):****Associate Editors:**

Dr S de Groot (Netherlands) Dr Marcel Dijkers (USA), Prof M Nakamura (Japan), Prof MWM Post (Netherlands), Prof J Steeves (Canada)

**Editorial Board:**

- Dr R Abel (Germany) , Prof F Biering-Sørensen (Denmark), Dr MWG Brinkhof (Switzerland), Dr SW Charlifue (USA), Prof A Curt (Switzerland) , Prof S Dunlop (Australia), Dr Julia Engkasan (Malaysia), Prof M Fehlings (Canada), Dr E Hagen (Norway), Dr Inge Eriks Hoogland (Switzerland), Prof A Krassioukov (Canada), Dr Emil Kostovski (Norway), Dr N Liu (China), Dr Euan McCaughey (Australia), Prof MJ Mulcahey (USA), Dr Ed Nieshoff (USA), Dr Tom Nightingale (Canada), Dr JG Prévinaire (France), Dr Jan Reinhardt (China), Dr R Rupp (Germany), Dr G Scivoletto (Italy), Dr Hyun-Ik Shin (Korea),

**Publication Manager:** Ms Mayumi Nagaishi (UK).

**Publishing Editor:** Mrs V Mercer(UK)

## **Submissions, Acceptance and Time to Decisions: Figures January – July 2019:**

Submissions 175 (2018: 179)

Number of Accepted Manuscripts 77 (2018: 79)

Number of Rejected Manuscripts 86 (2018: 105)

Rejection Rate: 52% (2018 57%)

Mean time to first decision *with* review (days) : 38 (2018: 25)

Mean time to first decision *without* review (days): 2 (2018: 2)

Mean time to secure all reviewers (days) : 20 (2018: 15)

Impact Factor: 1.89 (2018: 1.94)

### **Fairness and Transparency with all Decisions:**

- Introduced compulsory statement about Data sharing
- Compulsory statement about contribution of each author- but can't police
- Plagiarism – much better
- Salami publishing – still a problem but better
- Compulsory trial registration – paid an early price for this with drop off of clinical trials submissions but getting more now

### **Strategies to Attract Papers:**

- Letters were written to authors of Systematic Reviews (identified through PROSPERO) - some papers from this starting to be submitted
- Letters written to authors of clinical trials currently being conducted (identified through clinicaltrials.gov) - some papers from this starting to be submitted
- Have 3 Special Editions lined up for 2020/2021 – have not done this before!
- Invited authors to write editorials/papers – some come good, some do not!

### **Publicity:**

- Twitter ~ 1,000 followers
- FB ~ 1,500 friends
- Thanks to Sonja de Groot – posts nearly every day
- 4 awards for best papers in 2018
- Sponsoring awards at conferences
- Papers have social media metrics

### **Spinal Cord Series & Cases – Dr M Alexander (MA):**

#### **Associate Editors and Editorial Board:**

- Mindy Aisen
- Lance Goetz
- Dan Graves
- Claes Hultling
- Ruth Marshall
- Christina Rapidi
- Michael Stillman
- Chloe Slocum
- Martha Sliwinski

- Craig Alexander
- Brian Birch
- Ona Bloom
- Thomas Bryce
- Ian David
- Giulio Del Popolo
- Yannis Dionnysis
- Vernon Hill
- Ingebjorg Irgens
- Michael Kennelly
- Jorg Krebs
- Lesley Marson
- Peter New
- Sakina Rashid,
- U Singh
- Piotr Tederko
- Ceren Yerar-Fisher
- Jill Wecht
- Inge Blockmans, John Ditunno, Wagih El-Masry, Lisa Harvey- terms completed

**Journal Performance 2016-2019:**

- Number of manuscripts received 73-140- 161-96
- Number of papers accepted 43-97-107-77
- Number of papers rejected 24-35-55-29
- Time to first decision without review 12-4-3-5
- Time taken to secure reviewers 40-19-15-13
- Time to first decision with review 72-30-34- 29
- Acceptance rate 64%-74%-76%-74%

**Papers Published in 2018 and 2019:**

- 2017 time to online publication 37 days
- 2018-time to online publication 29 days
- 2019-time to online publication 15 days
- 2017 papers published 71
- 2018 papers published 110
- 2019 papers thus far 89

**2019-2020 Plan:**

- Need ideas and submissions from membership
- Will publish abstracts for meeting
- Continue with 4 pulse and point counterpoints annually
- Adding special collection for sustainability and SCI
- Looking for papers regarding quality of life and wellness
- Need reviewers and people for editorial board
- Contact me at scsc@iscos.org or spinalcordmd@live.com

## **REPORTS OF DISCIPLINE SPECIAL INTEREST GROUPS:**

### **Psychology Discipline Specific Working Group:**

- relatively new group
- held its first meeting during the Sydney meeting :

Approximately 30 psychologists, psychiatrists and social workers.

- Determined to undertake
  - pre-conference workshop for the Nice France
  - to explore the possibility of developing a psychological functioning data set.

### **Pre Conference Workshop:**

- Dr. Jane Duff - chair of the Pre-Conference Workshop sub-committee.
- Joint ISCoS and The European Spinal Psychology Association (ESPA) program on November 4, 2019
- Speakers for the workshop
  - Professor Ashley Craig,
  - Dr Imogen Cotter,
  - Dr Marion Gounelle,
  - Dr Marcel Dijkers and
  - Dr Tijin Van Diemann.
- Separate registration fee of 75 EUROS
- 24 people registered for the program.

Hope to make it an annual event at the yearly ISCoS meeting

### **Psychological Functioning Data Set:**

- Subcommittee –
  - Purpose: to develop a basic data set to be used when assessing psychological functioning and wellbeing of persons with SCI, inpatients or outpatients. The group may also recommend items, measures, and domains to be included in an extended data set for psychological functioning and wellbeing.
  - Chair: Dr Denise Tate.
  - Co-chair: Dr Marcel Post.
- Two teleconferences in September 2019.
- 28 members of the working group joined.
- Plans and goals :
- Focus on the development of psychological functioning data set (basic) for now
- Form a working group of those who truly can contribute to this task – To be discussed in Nice
- Consider domains for inclusion – the basic data set should be short and easy to administer yet contain the most critical items for an initial assessment.
- Consider specific measures or items for inclusion.
- Inform other members of this work and invite participation especially from representatives from developing nations: Newsletter

### **Liaison with ISCoS Education Committee:**

- Several members have participated in ISCoS affiliated Educational Workshops over the past year.
- Contributed on psychological and sexual issues to ISCoS workshops in Mongolia, Morocco, Miramar, India, Zambia, Uruguay and Malaysia.
- Two tele-medicine workshops were conducted during 2019 on sexual adjustment for consumers with SCI in Nigeria.

**Liaison with Quality of Life Special Interest Group:**

The Quality of Life SIG meeting, co-chaired by Drs Tate and Monden, will meet on Wednesday November 6<sup>th</sup> at 1:45 pm in the Erato Room and will include 3-4 presentations on projects related to quality of life.

Members of the Psychology Specific Working Group will be attending this meeting as well to discuss how our two groups might work closer together.

**Twitter:**

The Psychology Specific Working Group has set up a Twitter account for improved communication among psychosocial members.

Twitter handle: @ISCoS Psychsoc.

**Additional items that may be added to our agenda in Nice include:**

- Relationship with Quality of Life Taskforce
- Increased psychosocial presence at ISCoS
- Continuing education credits for psychologists at ISCoS
- Possible Changes in the ISCoS constitution that might impact the psychosocial members

**Plan of Action for 2019 Meeting:**

- Three presentations for our SIG meeting illustrating examples of current research on QoL being conducted at different sites – presenters include:
  - Jennifer Coker MS, MPH, Research Associate, Craig Hospital – Evaluation of a self-report method to obtain ASIA Impairment Scale Score in people with Traumatic SCI and their SCI-QoL ratings.
  - Cristina Anastasia Rapidi, MD, PhD, General Hospital, Athens, Greece – Quality of Life in Greece.
  - Tijn van Diemen PhD, University of Groningen, The Netherlands - Measuring Quality of Life during the Rehabilitation Phase.
- Discuss ideas for a possible workshop for the 2020 meeting
- Translation of the SCI-QoL BDS into various languages

**Quality of Life Discipline Specific Working Group:**

Denise G Tate PhD, Professor of PMR, University of Michigan Medical School, Chair  
 Kimberley R Monden PhD, Clinical Assistant Professor, Craig Hospital, Denver, Colorado, Co-Chair

**QoL SIG Mission:**

- To improve knowledge and education about Quality of Life (QoL) research among ISCoS members
- Promote a clear definition and measurement of QoL related to SCI
- Encourage collaboration activities among members

- Discuss comparative and cross cultural perspectives in QOL
- Discuss the role of QoL in SCI related trials

**2018-19 Accomplishments:**

- Three presentations on possible research collaborations related to QoL in SCI: 1) The SWISCI study; 2) Validation of the SCI-QoL Basic Data Set; 3) Wellspect HRQoL studies about catheterization.
- Three papers completed and submitted/accepted:
  1. New PW, Tate DG, Forchheimer MB, D’Andrea Greve JM, Parashar D, Post MWM. Preliminary psychometric analyses of the International Spinal Cord Injury Quality of Life Basic Data Set. Spinal Cord 2019 (e pub ahead of print)
  2. Post MWM, Forchheimer MB, Charlifue S, D’Andrea Greve JM, New P, Tate DG. Reproducibility of the International Spinal Cord Injury Quality of Life Basic Data Set: an international psychometric study. Spinal Cord 2019 (e pub ahead of print)
  3. Hakbiji van der Wind Aj, van Leeuwen CMC, Post MWM – What kwaliteit van leven betekent volgens mensen met een dwarslaesie: Kwalitatieve studie naar kwaliteit van leven van volwassenen met een dwarslaesie. Ned Tijdschr Revalidatiegeneeskd.

**Plan of Action for 2019 Meeting:**

- Three presentations for our SIG meeting illustrating examples of current research on QoL being conducted at different sites – presenters include:
  - Jennifer Coker MS, MPH, Research Associate, Craig Hospital – Evaluation of a self-report method to obtain ASIA Impairment Scale Score in people with Traumatic SCI and their SCI-QoL ratings.
  - Cristina Anastasia Rapidi, MD, PhD, General Hospital, Athens, Greece – Quality of Life in Greece.
  - Tijn van Diemen PhD, University of Groningen, The Netherlands - Measuring Quality of Life during the Rehabilitation Phase.
- Discuss ideas for a possible workshop for the 2020 meeting
- Translation of the SCI-QoL BDS into various languages

**Nurses Discipline Specific Working Group:**

**Group Members**

1. Andreas Wendl (Germany)
2. Debbie Green (UK)
3. Fiona Stephenson (UK)
4. Helen Kraft (Australia)
5. Letitia Graves (USA)
6. Neetu Maitra (India)
7. Randi Steensgaard (Denmark)
8. xx
9. xx
10. xx

There are 3 places available.

Please send in Applications if you would like to be considered

**Activities:**

Review of nurse modules for MOOC  
Consumer module - skin and pressure injury  
eLearn SCI- Translation into German

**Activities: MOOC**

Fiona Stephenson (UK. Chair)  
Veronika Geng (Germany)  
Mandira Baniya (Nepal)  
Randi Steensgaard (Denmark)  
Neetu Maitra (India)  
Neema Hassan (Jordan)  
Helen Kraft (Australia)  
Christa Schwager (Switzerland)  
Andreas Wendl (Europe)  
Letitia Graves (USA)  
Lim Su-Fee (Singapore)  
Stephen Muldoon (EDC Chair)  
Funding by ISCoS  
<https://www.scinurse.org/mooc.html>

**Examples of Collaborations by individual members of the Group:**

- AFSCIN
- ASCON
- MENASCI
- AO Foundation
- WHO
- HIFA
- NORDIC ADVANCED SPINAL CORD INJURY REHABILITATION COURSE (NASCIIR)
- MASCIP
- EUAN
- International Network of SCI Nurses
- Haiti SCI Working Group
- Nordic Network of SCI Nurses

**Occupational Therapy Discipline Specific Working Group:****Committee Members:**

Johanna Wangdell (chair) ,Sweden  
Veronika Vrbska , Czech Republic  
Elma Burger, South Africa  
Nicola Hunter, Australia  
Siiri Siimenson ,Estonia  
Kamrunnaher Koly,Bangladesh  
Jillian Swaine, Australia/Canada

**1. Formalise OT Committee**

1.1 Meeting structure ; 4 Web meetings; E- mails: The whole group and within working groups.

1.2 Formalize cooperation with PT, Nurse and Psychosocial Working Groups  
The Chairs of PT and Nurse SIG has been in contact at some occasions during the year to discuss mutual interests as pre workshop and educational issues.

1.3 Formalize the OT group within ISCoS  
Web meeting with the president of ISCoS

## **2. Advertise OT within ISCoS and spread OT specific SCI news:**

### **2.1. Facebook**

The OT Face book group. Advertised in several meetings around the world; South America, Middle East.

396 members

During Sep 19, 2019 – Oct 16, 2019 there were 248 active members.

Last 6 months: 1.25 posts / week

### **2.2 Webpage**

We maintain our webpage due to kind support from Swiss Paraplegic Center.  
[www.otsci.org](http://www.otsci.org)

## **3. Educational Activities**

### **3.1 OT MOOC**

Planning to run an OT specific MOOC. Based on E-learn SCI. University in Czech Republic interested to assist.

### **3.2 OT Network meeting during ISCOS congress 2019**

Proud to have invited two speakers as a complement to network and discussions.

## **Physiotherapy Working Group:**

### **Participation of Physiotherapists in ISCOS:**

#### **Previous situation**

- Therapists were finally accepted as full members
- No structures in place to accomodate discipline specific needs
- Development of a SCI related PT network (SCIPT/ Lisa Harvey) outside of ISCOS

#### **Activities last year**

- November 2018 AFSCIN Conference in Musaka, Zambia Organised by Rita Henn
- SCI Physiotherapy Workshop Guangdong China December 2018 running by Lisa Harvey

SCIPT meeting during the WCPT- Conference Geneva Mai 2019 **Current situation**

- Established participation at the meeting with PT specific workshop
- Integration of SCIPT (Web page still managed at the University of Sydney/Lisa Harvey; independent chairperson Rita Henn)

	<ul style="list-style-type: none"> <li>• Development of working group (Current chairperson Ulla Bergner)</li> </ul> <p><b>Vision</b></p> <ul style="list-style-type: none"> <li>• Co-operation with other discipline specific working groups( OT, Nurse).</li> <li>• Co-operation with the Education Committee.</li> <li>• Generate a Strategy for the Group and be part of ISCoS Strategic Planning.</li> <li>• Organize the SCRIPT meeting at ISCoS conferences and maybe a pre-conference workshop in future meetings.</li> <li>• Advocate of PT interests.</li> </ul>
	<p><b>ANY OTHER BUSINESS:</b></p> <p>The Editor of Spinal Cord Series &amp; Cases was hoping to publish the 2020 Abstracts.</p> <p>The President of ASIA confirmed they would like to continue to combine their efforts and collaborate more with ISCoS Committees.</p> <p>The Chair of the Canadian SCI Rehabilitation Association said they would like to partner with ISCoS on the 2021 ASAM. Agreed that this would be investigated.</p> <p>A member with an interest in Africa hoped there could be a joint conference in Africa one day. HC hoped we could look forward to many other joint meetings in the future.</p>
	<p><b>Adjourn: 18:04</b></p> <p><b>Next Annual General Meeting – Japan 2020. Details TBC</b></p>