

**Minutes of the ISSCD General Assembly hosted on Zoom  
26 July 2023**

**Present:** See registration list  
**Chair:** Dr Robert Anderson (President of ISSCD) RA  
**In attendance:** Heidi Urwin (Minutes) HU

NO.		ACTION	DUE
1	<p><b>Welcome from the President (RA)</b></p> <p>The ISSCD President, on behalf of the ISSCD Board, welcomed everyone to the General Assembly (GA) and introduced the ISSCD Board Executive, the secretary Elena Verdu (EV) and the Treasurer, Iris Jonkers (IJ). RA also thanked Esmee de Keijzer from Het Branche Bureau (HBB) and Heidi Urwin, Coeliac UK for their help in organising and hosting the GA.</p> <p>RA referred to a PowerPoint slide deck and provided a geographical breakdown of the current ISSCD membership; 34% The Americas and Canada, 24% Asia Pacific, 40% Europe, 2% Africa. He also provided information on members' profession (slide 5)</p>		
2	<p><b>Vote to approve the minutes of the General Assembly, Sorrento 21 October 2022</b></p> <p><b>Yes = 44</b>  <b>No = 1</b>  <b>Abstain = 4</b></p> <p>The minutes of the ISSCD General Assembly, Sorrento, 21 October 2022, were accepted as an accurate record.</p>		
3	<p><b>Financial statement – Treasurer Iris Jonkers (IJ)</b></p> <p>RA introduced the Treasurer Iris Jonkers (IJ) from Groningen University. IJ talked through the ISSCD financial statement of 2022 (slide 7).</p> <p>Knut Lundin (KL) asked a question regarding the €4,214.00 administration costs and if there was a more detailed breakdown. IJ explained that the €4,214 applied to the services provided by HBB and included the additional services provided prior to 2022. IJ went on to clarify that the costs were not only for administration but also for legal review of documents. Going forward the admin fees are expected to rise a little to pay for the infrastructure such as Microsoft 365 SharePoint, bulk emailing via MailChimp etc. The extent to any further legal and/or financial support is yet to be determined. IJ asked KL if that answered the question and KL confirmed it did.</p>		

NO.		ACTION	DUE
	<p><b>Vote to approve the ISSCD Financial statement 2022</b></p> <p><b>Yes= 64</b>  <b>No= 0</b>  <b>Abstain= 5</b></p> <p>The ISSCD Financial statement for 2022 was accepted as an accurate record.</p> <p><b>Financial forecast 2023</b>  IJ ran through the forecast of potential income and expenditure for ISSCD throughout 2023 (slide 9).  IJ asked if there were any questions.</p> <p>Kunt Lundin (KL) asked what the €9,107.00 income under coeliac disease alliance was in relation to and if there would be more money coming from Takeda. IJ explained it was the money the ISSCD had received (\$10k USD converted to Euros), as did the other Alliance partners ESSCD and SSCD, in support of establishing the Alliance. Also, IJ highlighted that the figures provided for 2023 were only a potential forecast not guaranteed income but there is an expectation that as the future plans of the Alliance develop, they would attract additional income. IJ asked if that answered the question to which KL replied yes it did.</p>		
4	<p><b>Announcement of the M-in-M awards</b></p> <p>RA introduced the ISSCD Secretary Elena Verdu (EV) from McMaster's University, Ontario, Canada to provide an update on the ISSCD's M-in-M programme.</p> <p>EV expressed pleasure at being able to share information about the M-in-M programme and thanked Takeda for its support with an educational grant.</p> <p>The inaugural call for the M-in-M programme opened at the end of March and closed 17 April, 2023. Twelve grants, each \$6k USD, have been awarded to the mentees.</p> <p>EV referred to the PowerPoint slide deck (slide 11) to introduce the twelve grant recipients and to the geographical spread of eth awards (slide 12). EV highlighted that n=7/12 involved an intercontinental exchange and that for any future call there would be a more targeted approach to marketing potential mentees in the Asia Pacific region.</p> <p>Marie Robert (MR) asked for clarification that the first listed country was the residency of the mentee, which EV confirmed to be correct. MR also asked if the mentees were all trainees. EV explained that not all mentees were trainees but the grant recipients also included individuals from countries where international exchange would be economically challenging, virtually impossible, without the support of the M-in-M programme. However, the majority of awards had been given to early career researchers.</p> <p>Govind Makharia asked if a call for applicants for the M-in-M programme would be offered more than once per year. EV replied that discussions were currently underway regarding a second</p>		

NO.		ACTION	DUE
	<p>round and further information would be available on the ISSCD website in due course.</p> <p>Knut Lundin asked if there was a reason why the Mentors had not been listed on the slide. EV informed everyone that information regarding mentors is available on the ISSCD website:  <a href="https://www.isscd-global.org/mentorship-programme/m-in-m-grant-recipients-july-2023/">https://www.isscd-global.org/mentorship-programme/m-in-m-grant-recipients-july-2023/</a></p> <p>There were no further questions so RA thanked EV and again thanked Takeda for its financial support with the M-in-M programme.</p>		
5	<p><b>ISSCD Objectives and restructure (slides 13-15)</b></p> <p>RA provided information on the background to the establishment of the ISSCD and how it had predominantly been involved in the hosting of the biennial International Celiac Disease Symposium (ICDS), although the organisation's objectives had a far wider remit. The ICDS has been very successful but it is not the ISSCD's sole purpose. RA explained that in 2019 there had been a constitutional change where the ISSCD shifted from an individual organisation to an umbrella organisation, with two Ex-Officio roles on the ISSCD Board, the President of the Society for the Study of Celiac Disease (SSCD) and the President of the European Society for the Study of Celiac Disease (ESSCD). As a result, Members of the ESSCD and SSCD could become registered members of ISSCD and the ISSCD was no longer able to charge membership fees.</p> <p>The new members of the ISSCD Board, October 2022, were concerned that the voting membership of ISSCD was not clearly defined outside the registered members of ISSCD and that this would make it difficult to execute its mission. Also, that the ISSCD Board lacked institutional memory following the 2022 Board election, albeit RA acknowledged that he had received a good handover from the previous President, Riccardo Troncone. The possibility of a high turnover of Board members, the main income being from the ICDS, which is unpredictable and the question around the ISSCD as an umbrella organisation meant the constitution was outdated.</p> <p>The ISSCD Board needed to address the issue and look to the future and the ISSCD Board proposed a revised constitution to advance the field.</p> <p>RA expressed how the ISSCD wanted its members to be more actively involved in the ISSCD and proposed to strengthen interaction and engagement through the creation of committees reporting into the Board.</p> <p>RA spoke to the changes of the revised constitution:</p> <p>Going forward there would be no ex-officio roles on the ISSCD Board but the relationship between the ISSCD, ESSCD and SSCD would be maintained through a proposed Strategic Alliance.</p>		

NO.		ACTION	DUE
	<p>In future the ISSCD Board will consist of n=8 members; A President, President Elect, Past President, Executive Officer and four other Board members. The Secretary and Treasurer will be appointed from the elected Board members.</p> <p>An option has been included within the Statutes to allow the ISSCD to underwrite the ICDS and other activities in the future. A financial plan is being worked on by the Board and will be shared in due course.</p> <p>Marie Robert (MR) asked what the difference between the ISSCD and ICDS is. RA explained that the ISSCD is the international society and the ICDS is the flagship international meeting of the ISSCD. MR referred to her professional organisation and how its annual meeting is named the same as the organisation which allows for greater clarity.</p> <p>RA explained how the ICDS had existed before the ISSCD was established. MR raised again the suggestion that the society and the meeting could potentially have the same name in the future.</p> <p>Govind Makharia (GM) asked about the new role of the Executive Officer (EO). RA explained that the EO straddled the Board and administration and would ensure that the objectives of the ISSCD are achieved. RA also added that the current Executive of the ISSCD Board is very active. He went on to further explain that the Board Executive's role is to govern whereas the Executive Officer has a management role and may have paid staff reporting into them in the future. The EO role has a renewable two year term by mutual agreement.</p> <p>GM stated that the Executive Officer role is appointed not elected to which RA replied, correct.</p> <p>Knut Lundin (KL) referred to the history of the ISSCD as interesting and that changes are good. He mentioned that the ISSCD had previously been criticised for the Board turnover being too low, then too high but now it is better defined. KL did not agree that the current constitution was all bad and that the ISSCD, ESSCD and SSCD had discussions regarding the M-in-M programme, prior to the new Board election in Sorrento, October 2022. KL expressed his ongoing concerns regarding overlapping interests and that if the new constitution was to create competition, he advised that it is rejected.</p> <p>RA confirmed that the new constitution did not cover that specifically but that there may be overlap e.g. in the work of the committees. KL replied yes, for instance.</p> <p>RA went on to say that the regional groups are not truly regional and that the constitutional change of the ISSCD in 2019 was not accordingly reflected by constitutional changes at the SSCD or ESSCD.</p> <p>RA asked KL if he had answered his questions to which KL replied yes. RA asked if there were any other questions.</p>		

NO.		ACTION	DUE
	<p>Michael Schumann, current president of the ESSCD, suggested that there may be chances of competition between the organisations but that there would be different focuses and since the advantages are big, the change in the ISSCD's constitution should be pushed forward.</p> <p>Iris Jonkers said it was important to highlight that there is a proposed Strategic Alliance between the ISSCD, ESSCD and SSCD and that the ISSCD's motivation for change was not competition but to build and advance the field and that the new Statutes would help to achieve that objective.</p> <p>Dan Leffler agreed with the point just made and believes that increased collaboration between the groups has the potential to increase opportunities (including funding) for all, rather than primarily setting up different groups to compete for a static amount of resources. Many other attendees at the meeting agreed with this point in the chat.</p> <p>Nadine Cerf Bensussan (NCB), agreed that the ISSCD needed to be stronger, that the coeliac disease community is a small community and that it is good to work together. NCB thanked the ISSCD Board for all its hard work and expressed an interest in the committees.</p> <p>RA explained that the revised constitution only specifies the ICDS organising committee and so it allows members to introduce other committees of interest to be approved and supported by the Board. RA mentioned that Fabiana Zingone had already show an interest in a committee dedicated to refractory celiac disease and ongoing issues.</p> <p>And that Govind Makharia had expressed an interest in a regional committee for Asia pacific.</p> <p>RA went on to mention that it can be costly for individuals to set up different individual groups but the ISSCD is offering the benefit of its infrastructure to support and facilitate the creation of such specialist committees.</p> <p>Knut Lundin asked if the ISSCD would consider having the Prolamin Working Group (PWG) within the ISSCD.</p> <p>RA commended the work of the PWG and its authoritative position and that he would very much welcome the alliance, since not enough is heard from the chemists. RA views the ISSCD as a hosting organisation, the Board only needs to receive an annual report, copy of meeting minutes. RA asked KL for his views as a long standing faculty member of the PWG.</p> <p>KL mentioned that he had previously raised the potential relationship between ISSCD and PWG and that the ISSCD is a natural connection. KL highlighted that the PWG needs to maintain its autonomy but being more closely aligned with the ISSCD would be a good thing. KL referred to the pending PWG meeting in October and that the connection with ISSCD would be raised. RA on behalf of the ISSCD Board said that this would be a</p>		

NO.		ACTION	DUE
	welcomed discussion and IJ who is attending the PWG meeting, looked forward to the discussion.		
<b>6</b>	<p><b>ISSCD revised statutes and vote to approve</b></p> <p>With no further questions RA moved to the approval of the ISSCD revised Statutes:</p> <p><b>Yes= 61</b>  <b>No= 1</b>  <b>Abstain= 5</b></p> <p>Two thirds of the vote are needed to pass the revised Statutes, this was achieved. RA considered the revised Statutes accepted and that the ISSCD would now move forward.</p> <p>KL asked if the ISSCD Board needed to rubber stamp the Statutes. IJ confirmed that the Board had already agreed to the revised Statutes and they would now be taken to the Notary for signing to become official. KL confirmed that was his understanding.</p>		
<b>7</b>	<p><b>Vote to release the Board of any legal responsibility for its implementation of policy in 2022</b></p> <p>Elena Verdu, secretary, introduced the vote to release the Board of any legal responsibility for its activities in 2022. IJ explained that this is an important requirement in the Netherlands and required of all such societies.</p> <p>Michael Schumann confirmed that the same is true in Germany.</p> <p>IJ asked if there were any other questions and as there were none, the vote was cast.</p> <p><b>Yes= 57</b>  <b>No= 0</b>  <b>Abstain= 2</b></p> <p>With a majority vote in favour, the ISSCD Board was released of its responsibility for policy implementation through 2022.</p>		
<b>8</b>	<p><b>ICDS Sheffield, 5-7 September, 2024</b></p> <p>At this point the General Assembly was over running by three minutes.</p> <p>RA confirmed the date and location of the ICDS 2024; 5-7 September, Sheffield. Prof David Sanders is the local organiser and currently on vacation so could not join the GA. RA promised that the programme would be refreshing and that the ISSCD aimed to reduce barriers for attendance and RA looked forward to seeing everyone at the event.</p>		
<b>9</b>	<b>Strategic Alliance</b>		

NO.		ACTION	DUE
	<p>RA referred to the Strategic Alliance between ESSCD, ISSCD and SSCD, that had already been referred to several times throughout the meeting and that an advanced draft of the collaboration agreement would be finalised soon.</p> <p>RA acknowledged and thanked the previous Board for its work in this area.</p>		
13	<p><b>AOB</b></p> <p>RA invited any other business / questions.</p> <p>Knut Lundin asked if the ISSCD membership database will be checked and if the organisation will try to attract new members. RA confirmed that members would be welcome from across the globe but this does not need to be exclusive and individuals do not need to give up memberships of other organisations, instead it will provide a greater opportunity to be involved.</p> <p>Nadine Cerf Bensussan asked for a link to the online membership application form and this was provided in the chat function of Zoom. <a href="https://www.isscd-global.org/forms/membership-application-form/">https://www.isscd-global.org/forms/membership-application-form/</a></p> <p>Michael Schumann stated the meeting had been very well organised and sent his thanks to ISSCD, Esmee at HBB and Heidi. In the Zoom chat many other attendees agreed with MS's comment. Knut Lundin also agreed with MS and said it was an impressive movement forward.</p> <p>David Armstrong stated that the new Statutes are a commendable formalisation of the mechanisms needed to allow continued development of the ISSCD. Well done &amp; congratulations to all! Many more attending the meeting agreed with this comment.</p> <p>Nelson Cheinquer, Takeda, offered his congratulations and looked forward to partnering!</p> <p>RA confirmed that the ISSCD website would be updated and IJ said this would include information about the M-in-M awards: <a href="https://www.isscd-global.org/mentorship-programme/m-in-m-grant-recipients-july-2023/">https://www.isscd-global.org/mentorship-programme/m-in-m-grant-recipients-july-2023/</a></p> <p>RA asked if there were any other questions or comments and there were none.</p> <p>RA closed the meeting by thanking everyone for their support and acknowledged the number who had engaged or submitted a proxy vote for the General Assembly was higher than any number recorded previously.</p>		

It is agreed that these minutes are a true representation of the meeting held on 26 July 2023.

Signed:

Date:

**Dr Robert Anderson (President of ISSCD)**

Seconded:  
[Name]

Date:



## Registration List ISSCD General Assembly 26 July, 2023

Name	In attendance or proxy
A dugna Negussie Gudeta	Attended
Alberto Caminero Fernandez	Proxy
Alina Popp	Attended
Amber Hann	Attended
Amy Russell	Proxy
Anil Verma	Attended
Annalisa Schiepatti	Attended
Anuj Sehgal	Proxy
Benjamin Lebwohl	Attended
Bob Anderson	Attended
Carolina Ciacchi	Attended
Catherine Raber	Proxy
Dan Leffler	Attended
David Armstrong	Attended
David Sanders	Proxy
Edgardo Smecuol	Proxy
Edwin Liu	Attended
Elena Verdu	Attended
Fabiana Zingone	Attended
Fakhreddin Sabooniha	Attended
Federico Biagi	Attended
Fernando Chirido	Proxy
Fiona Crockett	Proxy
Gaston Horacio Rueda	Proxy
Giada de Palma	Proxy
Govind Makharia	Attended
Gunj Bihari Gupta	Proxy
Haley Zylberberg	Attended
Heather Galipeau	Proxy
Heidi Urwin	Attended
Irene Marafini	Attended
Jason Tye-Din	Attended
Jennifer Iscol	Attended
Jennifer Sealey-Voyksner	Attended

Jernej Dolinsek	Attended
Jocelyn Silvester	Attended
Jorunn Stamnaes	Attended
Julio Bai	Attended
Kalle Kurppa	Proxy
Katri Lindfors	Attended
Kirsten Coppel	Attended
Knut E A Lundin	Attended
Lee Henneken	Proxy
Luca Elli	Attended
Ludvig Sollid	Proxy
Marco Constante	Proxy
Maria Ines Pinto Sanchez	Proxy
Marie Robert	Attended
Marilyn Geller	Attended
Marisa Stahl	Attended
Mark Wulczynski	Proxy
Melinda Hardy	Proxy
Michael Bordingj-Jorgensen	Attended
Michael FitzPatrick	Attended
Michael Schumann	Attended
Mohammad Rostami	Proxy
Nadine CERF-BENSUSSAN	Attended
Nelson Cheinquer	Attended
Nick Trott	Attended
Nicoletta Nandi	Attended
Olivia Moscatelli	Proxy
Penny Dellsperger	Proxy
Peter Green	Attended
Peter Prendergast	Proxy
Premysl Bercik	Attended
Rachel Kay	Attended
Renata Auricchio	Attended
Riccardo Troncone	Proxy
Ritu Verma	Attended
Ross McManus	Attended
Shruti Sharma	Attended
Silvija Cukovic-Cavka	Attended
Stiliano Maimaris	Attended
Valerie Byrnes	Attended
Yessica Pontet	Attended
Zrinjka Misak	Attended

