MINUTES OF THE EUROPEAN OSTOMY ASSOCIATION

MEETING OF THE HOUSE OF DELEGATES

8-9 April 2022, Hamburger Hof Hotel, Frankfurt, Germany

Theme: 'From Experiences to Solutions'

Friday 8 April 2022

1. **Welcome**: Pier Raffaele Spena, President of FAIS, Italy, welcomed all delegates, guests and sponsors to the 16th EOA Congress in Frankfurt. FAIS is delighted to host this special Congress, as it is the first time EOA Congress has ever been held online. He commented that today is a day where we can discuss many topics and thanked Jón Thorkelsson, ISILCO, Iceland and Maria Hass, Deutsche ILCO, Germany, for their input in today's event. He added that we do not forget our friends in Ukraine, and hope that peace will come soon in their lives.

Pier also thanked Roberto Aloesio and Louisa at FAIS for their work on this Congress.

2. **Official Opening**: The President of EOA, Jón Thorkelsson welcomed everyone to the 16th EOA Congress. He remarked that we are experiencing new things meeting online and we had hoped to meet in person. He thanked Roberto, Pier and the rest of the team, and acknowledged that it has taken time and effort to be here.

3. **The programme** for the remainder of Friday 8 April 2022 was:

* 'Ostomy in the World' presentation by C Pezcoller

* 'Narrative medicine-learning from patient experience to improve quality of life' by Maria Guilia Marini

* 'The role of the ECET' by Gabriele Krobath

* 'Stoma, job and sport' by Andrea Bondurri and Mattia Zamprogno

* 'Stoma and Food' by Anna Villarini and Guilia Villa

* 'Stoma, personal relationship and pregnancy' by Manuela Geercio

* 'The evolution of Stomatherapy – a well constructed stoma' by Prof John Nicholls

* Survey results were presented by Isabella Grosu, ASPIIR, Romania and Elżbieta Lesińska, EOA's webmaster.

Following these presentations the floor was open for all countries to share with the meeting any problems that are occurring for ostomates in their region and to explore current and future co-operations to support ostomates in need.

It was raised by South Africa that public sector struggle to get ostomy supplies and clinics are only supplying one brand. Faizel Jacobs, SASS, South Africa, asked how we could gather data collaboratively. Jón Thorkelsson suggested that we could find a Doctor or Nurse to do a study on

how ostomates in Europe and Africa are cared for. Abdo Abi Raad, Lebanese Ostomy Association, commented that in Lebanon the situation is bad because of the economic situation. Benjamin Lungu, commented that the situation in Zambia is bad too.

It was proposed that the African ostomy associations should collaborate. Jón Thorkelsson asked that they connect and list out what they need, then we can go through this via Zoom and try and put in some help.

Commented [MH-ILCO1]: In my opinion this is what is achieved.

ACTION: All African associations to send an email to Faizel on info@sasstomates.org.za

Inna Murtazina, ASTOM-Ukraine, passed their greetings to the attendees. She explained that ostomates receive no help on wards after surgery, and they do not have any stoma therapists. Patients are left to find everything out for themselves. The main issue in Ukraine is that the products are imported and expensive, with no state support.

FOWUSA (American ostomates) are happy to help with funding and supplies for Ukraine. A letter had been sent, but Inna believed this had gone to Kyiv rather than Odessa.

ACTION: Henning Granslev will look next week how else to help.

Maria Hass asked if it is possible for products to be stored or collected at the border and asked what is the best way to get supplies to Ukraine. Inna confirmed there is storage at Lviv and is better to send supplies to territory storage, and not to the borders. She suggested using the help of Consulate, as volunteers with cars get supplies to the territories.

Lerato asked if it would be possible to get copies of the day's presentations as they would like contact details of the surgeons/presenters. Jón Thorkelsson commented that he would ask FAIS to contact the speakers and ask if this is possible.

Roy Farstad, NORILCO, Norway, reported that in Norway they have 6,000 products to choose from but no stoma nurses. The stoma nurses have Masters Degrees but don't get jobs and become normal nurses. This is the same in Austria.

A question was raised about products for those with a Koch pouch. Now that the catheter is not being produced, what will patients do?

ACTION: Henning Granslev to call Roy Farstad after Easter

Jón Thorkelsson presented the new World Ostomy Award (this award follows the Coloplast Merit Award). The WOA is an international award for special projects of ostomy associations around the world. The money is given by Coloplast, the responsibility is held by EOA as an IOA region. The decision of the winners is taken by a jury of delegated members representing the three IOA regions, one person is from Coloplast. As the final item of the day Jón Thorkelsson announced to delegates that applications for the World Ostomy Award are now open. These are for projects yet to be held, and not retrospective. Closing deadline is 5th June 2022. Jon Thorkelsson directed delegates to the EOA website for details.

Saturday 9th April 2022

4. **Meeting of the House of Delegates**: The President called the meeting to order at 9.35am

5. **Minutes**: It was agreed that the minutes of the meeting would be recorded by Caroline Bramwell, IA, United Kingdom.

6. **Chair of the meeting**: It was agreed that the President of EOA, Jón Thorkelsson, would conduct the meeting.

7. **Roll Call**: The roll call was carried out by Jón Thorkelsson and from the member associations attending and proxy votes. The total votes possible was agreed as 22. As Lebanon were unable to register for the online voting, it was agreed that their votes would be delivered via message to Jón Thorkelsson on his phone.

8. **Acceptance of the Minutes of the last House of Delegates 2017**: No comments were raised on the 2017 minutes. Lerato Monyatsi of South Africa asked for a copy of the minutes to be sent later today so that they can read these, as they were not part of that meeting and would appreciate seeing these. Voting on the Minutes was to take place later during the online voting process.

ACTION: Minutes of previous meeting to be sent to Lerato Monyatsi.

9. **Presentations of Associations applying for membership**: Presentations were given by:

* Isabella Grosnu, of ASPIIR Romania, applying for Full membership;

* Jón Thorkelsson read through the Association of Ostomates Ireland slides as Mark Sheehy was having technical problems. He added that whilst the organisation were applying for Full membership, this was not possible at present as they were not registered. It was therefore accepted that they would be able to apply for Associate membership and become Full members when they had become registered. Mark Sheehy acknowledged he is OK with this action. Jón Thorkelsson acknowledged that he should have checked this when the application was first received.

* IAS du Lyonnais (France) and Provence Stomie Contact – this presentation was delivered by Maria Hass on their behalf as they do not speak good English. This presentation was supplied to Maria Hass in French language and she translated this for today's presentation. IAS du Lyonnais and Provence Stomie Contact are applying for Associate membership. Maria said she is happy both organisations have applied for membership and to France back in the EOA "family".

* Faizel Jacobs gave a presentation for SASS South Africa, which registered as a charity in June 2020. They are applying for Associate membership.

* No presentation was received from Tunisia. Jón Thorkelsson explained that they had not previously been accepted and was concerned that EOA had not heard from the Tunisia Association, which is run by doctors. He is aware Tunisia has internal problems. Ideally EOA would like to see this organisation run by ostomates. Tunisia Association are applying for Associate membership.

* A presentation was given by Zambia, who highlighted the struggles in the region and are applying for Full membership.

Voting on these applications were made later in the proceedings.

10. **Report on EOA Accounts**: The Treasurer, Jón Thorkelsson, presented the accounts for 2017 through to 2021, a copy of which can be found at Appendix 1. Voting on the accounts were made later in the proceedings.

He highlighted that every third year we expect to have a slight loss, but with assets in the bank we are still in a stable position. In Copenhagen we had elected three auditors, however, one resigned from EOA last year and therefore resigned as an Auditor. Another was too busy. Now Jane Halvorsen from NORILCO, Norway has signed these. Aila Ala-Aho, Finnilco Ry, Finland, became part of the accounting team and confirmed all were in order.

The Treasurer further highlighted that in 2020, due to Covid, we collected money in but had less expenses. Sadly, annual dues have gone down a little.

It was brought to everyone's attention that Bank Credit Suisse have increased their costs and have become very expensive. One of the tasks of the new EC is to appoint a new bank.

In the Professor Dr Gerhard Englert Fund account we are holding substantial sums which we can pay out to help projects. This was advertised early on but no applications had been received for this for some time. The Treasurer reminded members that this is available for them to apply for.

No questions were raised about the finances.

11. **EOA EC Report 2017-2022**: Isabella Grosu covered the report. We see new members joining this year and some resignations – The Bulgarian Ostomy Association and the Romanian Ostomy Association. The Treasurer asked for questions from the attendees. Delegates expressed their thanks to Henning Granslev and Marie Stéen, and expressed that they would be missed.

12. **EOA Registration**: Jón Thorkelsson explained that EOA needs to be registered as an Association so we need to go through some constitution changes. At first we considered having registration in the UK as it was English speaking. However, after the UK left the EU, we had to start again. We therefore looked at Germany as that is where the contact office is located. It is now important that we are registered in one country and follow the rules of that country. The proposed changes to the constitution are therefore based on the changes required to meet the obligations of that country.

Maria Hass introduced Christian Hobe, who is a lawyer, and explained the proposed changes to the constitution as shared in the papers prior to the meeting. He highlighted that we had to adapt the wording within the constitution so that those working in the tax office know what we mean. This does not change how we work.

Of particular note:

- Fees can only be collected from members. Therefore, applicants for membership are no longer required to pay the annual subscription fee upfront.

- In Germany you still have to be together in person to make decisions. Therefore an exemption law was created during the pandemic. Clause 5.5 means we can now make decisions without having to meet in person, as long as anyone who has a right to vote, can vote via email, phone etc.
- Clause 7 is an important change to the constitution, as it is required. As EOA receives tax privileges in Germany, should it be dissolved, all remaining money has to go to another 'selflessly working' organisation in Germany. This is made after liabilities are paid. Anything left must go to another tax exempt organisation.

Some questions were raised. Christian Hobe confirmed we would NOT be exempt from VAT on costs but only on Tax on income. He also confirmed that EOA can pay salaries where they are properly contracted, He also clarified, that further limitations can be made for the Executive Board, e.g. contracts with a value of more than €5.000 require two signatures.

A question was raised about whether, in the case of dissolution, money could be donated to members before liabilities to minimise any money going to another German Association. The EOA would be able to spend all its money for purposes covered by their constitution, before the dissolution. This may include donations.

A question was asked about whether those in the House of Delegates both need to be ostomates. The wording says 'should'. Caroline Bramwell, IA, UK, explained that 'should' means in best practice but not essential. Jón Thorkelsson proposed that at least one is an ostomate; it is up to us to speak for ourselves as ostomates and not have professionals speaking for us.

Maria Hass thanked Christian Hobe. for his good work on the constitution.

13. **Voting process**: The process of the how online voting would proceed was explained and those who could vote accessed a separate online 'room' to cast their votes.

The voting results were:

Acceptances of Minutes of 2017:	Yes – 19	No – 0
Provence Stomie Contact France Associate Membership:	Yes – 20	No – 0
IAS due Lyonnais France Associate Membership:	Yes – 17	No – 0
Association of Ostomates Ireland Associate Membership:	Yes – 16	No – 0
ASPIIR from Romania Full Membership:	Yes – 19	No – 0
The South African Society of Ostomates (SASS) Associate Membership	Yes – 20	No – 0
Tunisian Ostomy Association Associate Membership	Yes – 16	No – 2
Stomacare Support Zambia	Yes – 18	No – 0
Approval of EOA Accounts	Yes – 19	No – 0
Approval of changes to EOA Constitution	Yes – 19	No – 0

14. **Election of Executive Council**: Susanne Deimel-Engler, Oesterreichischer ILCO Stoma-Dachverband took control of the elections of the new EC, in the capacity of election of nomination representative.

The nominated candidates were Jón Thorkelsson, ISILCO, Iceland for the position of President; Maria Hass, Deutsche ILCO Germany; Caroline Bramwell, Ileostomy & Internal Pouch Association UK; Isabella Grosu, ASPIIR, Romania; Salvatore Battaglia, A.I Stom, Italy.

Each of the new proposed EC made a short presentation before voting.

Votes for election of the new EC were:

Jon Thorkelsson	20 votes
Maria Hass	20 votes
Isabella Grosu	20 votes
Caroline Bramwell	19 votes
Salvatore Battaglia	9 votes

As a result of the voting Jón Thorkelsson was elected as President, Maria Hass, Isabella Grosu and Caroline Bramwell were elected to the EC. Unfortunately, as Salvatore Battaglia did not reach the sufficient number of votes, he was unable to be elected.

15. **Election of nomination representative for 2025 elections**: As Susanne Deimel-Engler is stepping down, we thank her for her hard work. The EC proposed that Henning Granslev and Marie Stéen take on this role. This was accepted by attendees.

The appointed EOA Webmaster Elżbieta Lesińska had been confirmed again. Jón Thorkelsson thanked her for her excellent support during the last years.

16. **Next EOA Conference**: At present only one offer has come from Norway, to be hosted in Bergen on the west coast of Norway. No decision was made on the day but will be discussed. Any other countries should submit their tender if they wish to be considered.

17. **Matters Arising**:

World Ostomy Day – discussions were had around whether this should be held every year, alongside the annual World Ostomy Award, with everyone using the same theme and slogan across the world. Jón Thorkelsson confirmed this had been discussed amongst the EC and advised that this would not be EOA's decision and would have to be made by IOA. It was suggested that countries could celebrate in their own countries and us the logo. The question was asked if countries can use the words 'World Ostomy Day'. It was confirmed that if they are an EOA member then they can do this in their own country. Jón Thorkelsson suggested that people look to enter the World Ostomy Award to win the prize funds.

Directory – Maria Hass asked that members check their contact data on the website in the next few days and notify the webmaster with any changes.

18. **Close of Business**: Jon Thorkelsson closed the meeting by saying that this has been a very special conference and we thank FAIS and the technical team for arranging this. Minor technical problems were sorted very quickly and we came through it alive and kicking.

His final words were in recognition of contribution to EOA by Henning Granslev and Marie Sten. It is a serious thing to lose two valuable people from the EC. Thanks were given to both for their hard work and they were presented with some Icelandic wine in appreciation.

Marie Sten thanked everyone in the EC, acknowledging it had been fun working together.